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PRINCIPAL INVESTIGATOR: Roshan Bastani, Ph.D.

CONTRACTING ORGANIZATION: University of California

Los Angeles, California 90095-1406

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13. ABSTRACT (Maximum 200 Words)

The purpose of this study is to conduct telephone surveys with first degree relatives of prostate cancer cases to obtain information on knowledge, behaviors and psychological distress associated with risk status. In the first year of the study we have conducted a total of 13 focus groups with men from four ethnic groups (52 African Americans, 39 Caucasian, 29 Hispanic, 20 Filipino). In addition, we have pilot tested our recruitment procedures, contact materials and the telephone survey with 80 prostate cancer cases (20 per ethnic group) and their relatives. Based on the focus group and pilot test findings, we have finalized our recruitment materials and the survey in English and Spanish. Assisted by a marketing company, we have developed four different versions of all contact materials for cases and relatives and the intervention brochure for African Americans, Whites, Hispanics, and Asians. To date, we have obtained from the Los Angeles County Surveillance Program over 6000 prostate cancer cases diagnosed in 1997 and 1998. We have set up tracking databases for cases and relatives and have programmed our Computer Assisted Telephone Inerviewing System. We have contacted over 1900 physicians and have sent contact materials to the first batch of cases (N=330).

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FOREWORD

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PI - Signature

Date

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Fund #DAMD17-98-1-8566 Author: Roshan Bastani, Ph.D.

(5) Introduction

The purpose of this study is to obtain information on what high risk (a family history of prostate cancer) men know and feel about prostate cancer. The research questions to be addressed include: What do high-risk men know about prostate cancer? What is the level of psychological distress associated with knowledge of risk status? What is the personal cost-benefit ratio for these men when balancing their increased risk for the disease against the morbidity associated with treatment? What are the rates of usage of DRE and PSA in this population? What are the prevalent attitudes and beliefs in this group regarding prostate cancer screening and participation in clinical trials? Are there differences in knowledge, attitudes, behaviors, and psychological distress between different ethnic groups? What demographic, health care system, knowledge, and attitude factors are related to participation in screening and willingness to participate in clinical trials? We will use a population-based cancer registry, the Cancer Surveillance Program (CSP) of Los Angeles, to obtain a sample of prostate cancer cases diagnosed in Los Angeles County over a two year period. We have been funded to conduct surveys with 250 African American and 250 White relatives. However, because we are lacking information on other ethnic groups as well, we will attempt to recruit and to conduct additional surveys with 250 Hispanic and 250 Asian first degree relatives. We will contact cases to request relative information. We will then contact relatives and ask them to participate in a brief survey, by telephone, on prostate cancer.

(6) Body: Progress Report on first year of funding

The funding for this study was received at the end of October 1998, which reduced the first year of the study to 10 months. We have almost completed Task 1, and have started activities related to Tasks 2, 3 and 5. The following section describes some of the major accomplishments associated with each task.

Task 1

Focus Groups

In the past year, we completed a total of 13 focus groups for purposes of development and testing of the questionnaire.

The focus groups were broken down as follows:

Ethnic Group	# of Groups Conducted	# of Participants
African Americans	5	52
Hispanics	3	29
Asian (Filipino)	2	20
Caucasian	3	39

African American men were recruited through two popular local Methodist churches and one senior center. Hispanic men were recruited through a downtown Los Angeles homeless health care center. Filipino men were recruited through a local Filipino organization. Caucasian men were recruited through an adult center.

All groups were conducted by Carolyn Rowley, an African American member of our staff. She was assisted by Mr. Yochanan Israel, an African American male health educator from a local community health organization. At the conclusion of the focus group discussions, Mr. Israel provided participants with a short educational workshop on prostate health and cancer. Dr. Nilsa Gallardo, a Hispanic researcher on our team, assisted in conducting the Hispanic groups and facilitated translation in the groups. Ms. Jing Vida, a Filipino project manager in our Division, assisted in the Filipino groups.

The focus groups were aimed at understanding how much high-risk men know about prostate cancer. The areas of discussion included:

- knowledge about prostate cancer (causes, risk factors, tests, implications of having prostate cancer);
- barriers to testing (concrete, emotional, lack of knowledge)
- recommendations by others to get tested (physician, family members, friends)
- intentions to get tested
- impact of having a relative with prostate cancer on likelihood of getting tested
- likelihood of completing a brief survey via telephone (why? why not?, approaches that might make participation more likely)
- knowledge concerning clinical trials

We also administered several questionnaire items to the groups and asked for their feedback on degree of clarity of questions, level of understanding of questions, openness to

answering such questions. We described the proposed format of the study (i.e. telephone survey study, recruitment through family members, length of survey) and asked participants their opinions and suggestions on how to ensure successful recruitment of subjects.

Some of the major findings of the focus groups were as follow:

- Overall, men of all ethnic groups expressed a general reluctance to visit a doctor unless they were experiencing major symptoms.
- Older men tended to have physicians more often than younger men, and therefore made more regular visits.
- Most men had only a very general understanding of what the prostate is, where it is located, and its function.
- Most men were familiar with the digital rectal exam (DRE), but unfamiliar with the PSA.
- Among men who had physicians and made regular visits to them, the majority were unsure whether they were receiving the PSA test.
- Among African American and Hispanic men there was a general mistrust of physicians.
- African American men were skeptical about the reasons physicians might be testing them.
 Among African American men the Tuskeegee experiment was cited as a reason for mistrust of doctors.
- Hispanic men felt that it was a weakness to be sick, and this was somehow associated with likelihood of getting screened.
- Most men spoke about the embarrassing nature of the DRE.
- A large number of men listed cost as a barrier to seeing a physician.

Survey Questionnaire

We used focus group findings to guide us in modifying and finalizing our survey. For example, several questions were revised to facilitate understanding (i.e. psychological distress questions Q24-28, sigmoidoscopy Q42). Other questions were omitted in an effort to limit the length of the survey. Items were also added in the areas of beliefs, risk factors, and costs v. benefits. The following domains, based on the Adherence Model, were included in the survey:

- Medical History
- Family History of Prostate Cancer
- Psychological Distress
- Past Adherence
- Communication with Doctor
- Demographics
- Knowledge of Risk Factors
- Perceived Susceptibility
- Beliefs in Benefits vs. Costs
- Subjective Norms
- Fatalism

- Social Supports
- Insurance
- Knowledge of Screening Guidelines
- Past Adherence in, Intentions & Knowledge of Clinical Trials

Two scenarios on PSA testing where also included. These scenarios were essentially identical but for the order in which the information was presented. In the first scenario we present the controversy over the accuracy of the test and elevated PSA levels. This information is followed by the fact that the PSA is the only test currently available and, therefore, many doctors recommend it for men over age 40. The second scenario reverses these two pieces of information. Each scenario will be randomly administered to 33% of the sample. The final 34% of the sample will not receive a scenario. We are planning to test the effect of the scenario on subsequent questions regarding intention to inquire about screening and intention to get a PSA within the next 12 months.

Pilot Testing of Survey

Using the lists of prostate cancer cases provided to us by the Los Angeles County Surveillance Program, we randomly selected 20 cases from each of the four major ethnic groups (African American, Hispanic, Asian, and White) to contact for relatives' names. However, we were only able to reach approximately 45 men. Of those, 11 agreed to provide us with relatives names. The remainder of those men contacted either did not speak English or Spanish, did not have living first degree male relatives, did not have relatives living in the United States, or refused to participate. The remaining 35 or so men could not be reached (contact letters returned undeliverable, telephones disconnected, wrong numbers), We believe that a big contributor to the low rate of participation is the fact that we only contacted men who had no physician listed in the Registry database. This was done, in order to save time, because for this subgroup no physician letters are required. However, this could have adversely affected the response rate.

We conducted a total of 9 surveys with relatives of cases. Overall, if we were able to reach them, relatives were generally willing to participate in and complete our survey. Despite feedback from our focus groups that we should keep the length of the survey down to a maximum of 10 minutes, all men who participated in the pilot study completed the survey, which on the average took 25 minutes, without complaint.

At this time, the survey questionnaire has been finalized and translated into Spanish. It is currently being programmed into our Computer Assisted Telephone Interviewing (CATI) database in both languages. We are planning to trouble-shoot and pilot test the CATI questionnaire within the next four weeks, before starting large scale interviewing.

Task 2:

Recruitment

To date, we have received a total of 6328 prostate cancer cases (after deleting duplicates) who are still alive. Four thousand four hundred and fifty-two cases were diagnosed in 1997 and 1875 cases in 1998. Originally we had proposed to contact cases diagnosed in 1998 and 1999. However, because of the low number of Asian cases diagnosed per year, we have expanded our recruitment criteria to include 1997. This turns out to be beneficial for the study overall, because reporting of the 1997 cases is much more complete than that of the 1998 cases. We are receiving new cases from the Los Angeles Cancer Surveillance Program every two months. We have already sent letters (and if needed a second request letter) to the physicians of 1900 patients to inform them of the study. Physicians of 81 patients have recommended we not contact the cases for various reasons, and 25 cases were identified as deceased. We have updated our databases accordingly.

We plan to contact cases by month and year of diagnosis, e.g. Batch 1 will be cases diagnosed in January and February of 1997 (99 African Americans, 91 Hispanics, 40 Asians, and 100 Whites). Stratified random sampling has been used to select 100 White cases from the expected 556 in 1997. Age has been used on the stratifying variable, with 20% of cases being selected from those diagnosed before age 60. Contact materials (see below) have been developed and the first batch of 330 cases have already been sent our recruitment materials.

Special Recruitment Strategies for Non-White Cases and Relatives

In our focus groups and pilot testing of the survey, we asked participants to review and rate samples of possible contact and recruiting materials. Based on these responses we concluded that a personalized and ethnically targeted approach would be an effective method for inviting participation into our study. We, therefore, approached a marketing company to help us design attractive and ethnically specific invitational brochures which will be sent to both cases and relatives. Case brochures will ask cases to participate in the study by providing us with the names of their first degree relatives. Relative brochures will ask relatives to participate in the study by completing a telephone survey. Four different case and relative brochures have been developed, one each for Black, White, Hispanic and Asian cases and relatives. Each brochure is ethnically specific in that it portrays photographs of men of a particular ethnic group. Additionally, the respective brochures specifically address each ethnic group directly (i.e "We at the Healthy Families Project are committed to recruiting African American men such as yourself." - See attached examples). These materials will be sent along with a cover letter on UCLA stationary. which will be signed by Dr. Bastani and another member of the research team (Dr. Clarence Bradford for African Americans, Dr. Mark Litwin for Whites, Dr. Nilsa Gallardo for Hispanics, and Dr. David Huang for Asians). Each letter is personalized and directly addresses the case or relative by name.

Task 3

Telephone Interviews

We have trained male and female interviewers on how to conduct the telephone surveys. The training was done by Dr. Gallardo, a licensed clinical psychologist, who has experience in conducting interviews and in interview training. Interviewers were trained in the basic techniques needed to engage an individual by telephone and obtained the needed information. The training focused on the unique challenges faced when approaching someone by telephone as opposed to in person. Special emphasis was placed on attentive listening, reflecting, maintaining a positive tone of voice, sensitivity to the needs and concerns expressed by the individual, and cultural styles. Training consisted of 12 hours of education during which basic skills and techniques were reviewed and role-plays conducted. Training addressed potential issues when contacting cases for relative information as well as contacting relatives for the survey.

Task 5

Databases

We have developed tracking databases for case and relative recruitment. These databases will allow us to track, among other things, the following:

For Case:

- case ID and name
- address and phone number
- ethnicity
- age
- age of diagnosis
- physician consent to contact case
- physician reason for not consenting
- dates contact letters sent
- case responses
- number of telephone attempts to reach cases
- case consent to contacting relative
- number of living relatives (father, brothers, sons)
- contact information for relatives

For Relatives:

- relative ID and name
- case name
- relative ethnicity
- address and phone number
- age

- knowledge of case's prostate cancer
- preferred language for survey
- dates contact letters sent
- relative written responses
- number of telephone attempts to reach relative
- consent to participate
- if not willing to participate, reasons why not

Because we will use a Computer Assisted Telephone Interviewing (CATI) system to conduct the telephone surveys on computer rather than paper and pencil, we expect high quality data. The CATI program not only allows the interviewer to input survey information directly into the computer but also allows for managing of calls, controlling quotas, monitoring call dispositions, consolidating data, and tracking interviewer productivity. Advantages of using the CATI include: reducing interviewer error in following questionnaire skip patterns (skips are made automatically by the computer); eliminating out of range responses and missing data (a valid response is required in order to proceed to the next screen); eliminating the need for coding of most data; and immediate access to response frequencies at any time-point in the project. The CATI system generates daily production statistics and detailed reports of interviews completed during the session as well as refusals, scheduled call backs, and non-working phone numbers.

(7) Key Research Accomplishments

- conducted 13 focus group with a total of 140 men
- developed, pilot tested and finalized the survey questionnaire
- translated questionnaire into Spanish
- developed cover letter and study abstract for mailings to physicians
- developed cover letter and ethnically specific brochures for cases and relatives
- translated all project documents into Spanish
- programmed questionnaire for Computer Assisted Telephone Interviewing (CATI)
- obtained prostate cancer cases diagnosed in 1997 and 1998
- contacted physicians of cases diagnosed between January and April 1997-98
- developed tracking databases for case and relative recruitment
- trained male and female interviewers in study objectives, content of telephone survey, basic probing techniques, cultural sensitivity and communication skills, respondent follow-up protocols and CATI operations

(8) Reportable Outcomes

N/A

(9) Conclusion

During the past year the development and finalization of recruitment documents and survey were completed. Additionally, pilot information was obtained from over 140 men on their thoughts, beliefs, and screening practices relating to prostate cancer. Overall, we found men to be fairly open to, and interested in, discussing this health issue. We do not anticipate any difficulties meeting our target recruitment numbers, particularly since our subjects will be informed that we obtained their names from their relatives. Based on experience from our previous studies, the most difficult task we anticipate is obtaining a sufficiently high response rate from cases. It remains to be seen if our efforts to incorporate culturally-specific materials and to provide our interviewers with cultural and gender-sensitive training, will be as successful as we expect.

(10) References

N/A

APPENDICES

FIRST PHYSICIAN CONTACT LETTER

20 September 1999

Dr. FIELD(fname) FIELD(mname) FIELD(lname) FIELD(address1) FIELD(address2) FIELD(city), FIELD(state) FIELD(zip)

Dear Dr. FIELD(Iname):

The Division of Cancer Prevention and Control Research at the UCLA Jonsson Comprehensive Cancer Center is conducting a research study which involves telephone interviews with first-degree relatives of prostate cancer patients. Individuals whose name were obtained from the Los Angeles County Cancer Surveillance Program will be asked to provide the names of their first-degree relatives, who will then be contacted to request their participation in the study (see attached abstract).

Since cancer is a reportable disease, information on all cases diagnosed in California is maintained by the California Tumor Registry. The Los Angeles County Cancer Surveillance Program, a member of the California Tumor Registry, has agreed to provide which is mandated by state law. The state registry has agreed to provide us with information necessary to contact cases. This study has received approval from UCLA's Committee for the Protection of Human Subjects.

I am writing to inform you that your patient(s) listed on the attached form is/are among those scheduled to be contacted. If you are aware of any circumstances we should be aware of before contacting the patient(s), please let me know. If we do not hear from you we will proceed to contact the patient. Also, we would appreciate it if you verified the address(es) on our form with your records and provide us with the current information if discrepancies exist. Please check the appropriate column for each patient listed and return the signed form in the enclosed envelope.

I sincerely thank you for your time and effort. If you have any questions, please contact me at 310.206.9266.

Sincerely,

Roshan Bastani, Ph.D. Principal Investigator

Dr. R. Rastani

RB:cr Enclosure (2)

A Study of Men with a Family History of Prostate Cancer Principal Investigator: Roshan Bastani, Ph.D.

This study is targeting men, with a family history of prostate cancer, who are at substantially increased risk for developing the disease compared to other men of the same age without a family history. and are therefore important targets for cancer control research. However, the almost complete lack of information regarding the knowledge, attitudes, psychological distress and decision making processes around prostate cancer in this high-risk group is sure to undermine even the best intentioned intervention efforts. The proposed study attempts to correct this situation by conducting a theory-driven telephone interview study of a population-based sample of 250 each African American, Hispanic, Asian, and white first-degree relatives of prostate cancer cases.

Using a population-based cancer registry, we will obtain all prostate cancer cases diagnosed in L.A. County over a four year period. After contacting the physician on record, we will contact the cases to identify and seek permission to contact eligible first-degree male relatives. Using this procedure, we will obtain a sample of fathers, brothers, or sons of prostate cancer cases, 40-70 years of age, who themselves have not had prostate cancer. We will conduct Telephone Interviews with all eligible and willing relatives to obtain information on knowledge, attitudes, behaviors and psychological distress associated with risk status.

The data obtained from this study will be used to explore a number of critical research questions, including the following: What do high risk men know about prostate cancer? Do they understand the risk factors for this disease and their personal risk? Are they aware of and understand the current controversy regarding screening and treatment? What is the level of psychological distress associated with knowledge of risk status? How does the distress influence behavioral choices regarding screening and participation in clinical trials? What are the screening rates in this population (DRE and PSA) and how was the decision to be screened made? What are the prevalent attitudes and beliefs regarding prostate cancer, screening, and participation in clinical trials? Are there ethnic differences in knowledge, attitudes, behaviors, decision making and psychological distress?

What we learn from this study will be of great importance in guiding intervention development, for example, to encourage informed decision making regarding screening or to reduce psychological distress. Additionally, this information will benefit clinicians who must make daily decisions regarding whether or nor to offer screening to asymptomatic men. Policy makers will also find this information useful as they grapple with the issues of setting guidelines and standards for prostate cancer screening and treatment.

PHYSICIAN REMINDER LETTER

April 19, 1999

Dr. FIELD(fname) FIELD(mname) FIELD(lname) FIELD(address1) FIELD(address2) FIELD(city), FIELD(state) FIELD(zip)

Dear Dr. FIELD(Iname):

Recently, we at the Division of Cancer Prevention and Control Research (DCPCR) at the UCLA Jonsson Comprehensive Cancer Center sent you a letter informing you that we have received the name(s) of your patient(s) listed on the attached sheet from the Los Angeles County Tumor Registry and were interested in contacting him/them. We are contacting the patient(s) in order to obtain the names of first-degree relatives, who will then be contacted and asked to participate in a telephone interview.

To date we have not received a response from you to our previous letter. Our experience suggests that many physicians who do not respond have no objections to their patients being contacted, but simply do not have the necessary time to respond to our inquiries.

We are anxious to contact your patient(s) and would appreciate your advising us (by telephone or by sending back the enclosed form in the postage-paid envelope) if such contact is ill-advised or if you have objections or reservations about our contacting the patient(s). We would also appreciate your verifying the address(es) on our form with your records and providing us with the current information if discrepancies exist. If we do not hear from you within two weeks we will assume that we may proceed and contact the patient(s).

Thank you for your time and effort. If you have any questions, please contact me at 310.206.9266.

Sincerely,

Roshan Bastani, Ph.D. Principal Investigator

Dr. R. Rastani

RB:cr Enclosure BERKELEY · DAVIS · IRVINE · LOS ANGELES · RIVERSIDE · SAN DIEGO · SAN FRANCISCO



SANTA BARBARA · SANTA CRUZ

September 14, 1999

FIELD(ptfname) FIELD(ptlname)
FIELD(paddres1)
FIELD(ptcity), FIELD(ptstate) FIELD(ptzip)

DIVISION OF CANCER PREVENTION AND CONTROL RESEARCH
DEPARTMENT OF HEALTH SERVICES
SCHOOL OF PUBLIC HEALTH
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BOX 956900
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(310) 825-3181 FAX (310) 206-3566

Patricia A. Ganz, M.D. Director (310) 206-1404

Roshan Bastani, Ph.D. Associate Director (310) 206-9266

Dear Mr. FIELD(ptlname):

We need your help to fight prostate cancer. We invite you to join the UCLA Division of Cancer Prevention and Control in a research study on prostate cancer. We got your name from the Los Angeles County Cancer Surveillance Program because you have had prostate cancer.

As you may know, close relatives of people who have had prostate cancer are more likely to get prostate cancer. We would like to talk to your close family members about what they know and how they feel about prostate cancer and its early detection, even if they themselves do not have prostate cancer.

We have a form that we would like you to fill out and return. Please take a few minutes to look at the enclosed material as you make your choice to be involved. Your participation is completely voluntary. Your choice to take part will not affect the services you receive from your doctor or the Los Angeles County Cancer Surveillance Program.

We hope you choose to be part of this study. You can make a difference in the fight against prostate cancer. Thank you for your time and caring.

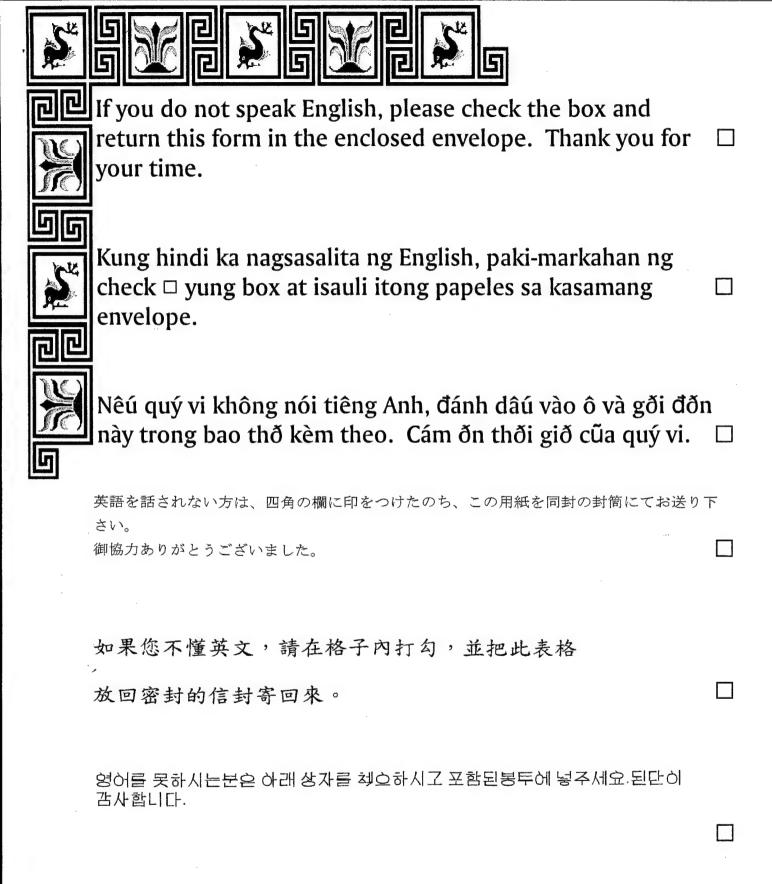
Sincerely,

Roshan Bastani, Ph.D.

Dr. R. Bartan

Mark Litwin, M.D.

Hork & Lituri MD



UCLA Healthy Families Project • 650 Charles Young Dr. A2-125 CHS • Box 956900 • Los Angeles, CA 90095-6900

Family Information



HEALTHY FAMILIES



Prostate Cancer Prevention Project University of California, Los Angeles

VOID EATHED.			
YOUR FATHER:	Name	· · · · · · · · · · · · · · · · · · ·	Age
	Street address		
	City State Z		
	() Telephone		
•	had prostate cancer?		
Did you ask his per May we contact him	rmission before giving us his name? Yes m for this study?		
If no , please tell us	s why not.		
Which language de	1		
willen language uc	oes he prefer for an interview?		
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	-		
□ English □ Spa	-		
□ English □ Spa	-	Age	
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□ English □ Spa BROTHER: Does he know you Did you ask his per May we contact his	Name Street address City State 2 (Zip No □ No □ No	
□ English □ Spa BROTHER: Does he know you Did you ask his pe May we contact his	Name Street address City State 2 (Zip No □ No □ No	

FIELD(prproject), FIELD(pethnic1), FIELD(PTID)

BROTHER:						
	Name					Age
	Street address		***************************************			
			VI-2-2-2-2-2-2-2-2-2-2-2-2-2-2-2-2-2-2-2		-	
	City	tate	Zip			
	Telephone					
Does he know you had r			Yes		No	
	ion before giving us his nar	ne?	Yes		No	
May we contact him for	this study?		Yes	Ц	No	
If no, please tell u	s why not.					
Which language does he	prefer for an interview?					
	☐ Spanish ☐ Other					
_	-					
(ADULT)						
SON:	Name				Age	
SON:					Age	
SON:	Name Street address				Age	
SON:	Street address	tate	Zip		Age	
SON:	Street address	tate	Zip		Age	
SON:	Street address City S	tate	Zip		Age	
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Does he know you had p	Street address City S () Telephone prostate cancer? ion before giving us his nar		Yes Yes		No	
Does he know you had p Did you ask his permiss	City s City s Telephone prostate cancer? ion before giving us his nar this study?	ne? □	Yes Yes Yes		No No No	
Does he know you had p Did you ask his permiss May we contact him for If no , please tell us why	City S City S	ne? □	Yes Yes Yes		No No No	
Does he know you had p Did you ask his permiss May we contact him for If no , please tell us why Which language does he	City S City S	ne?	Yes Yes Yes		No No No	

Returned by: FIELD(PTFNAME) FIELD(PTMNAME) FIELD(PTLNAME)

(ADULT)		
SON:*		Age
Street address	7 27 27 27 27 27 27 27 27 27 27 27 27 27	
City State	Zip	
() Telephone		
Does he know you had prostate cancer?	□ Yes	□ No
Did you ask his permission before giving us his name?		□ No
May we contact him for this study? If no , please tell us why not.	□ Yes	□ No
It no, piedse ten us why not.		- Contract
Which language does he prefer for an interview?		
☐ English ☐ Spanish ☐ Other		
(ADULT) SON:*		
Name		Age
Street address		
City State		
City State		Zip
Telephone		
Does he know you had prostate cancer?	□ Yes	□ No
Did you ask his permission before giving us his name?	□ Yes	□ No
May we contact him for this study?	□ Yes	□ No
If no, please tell us why not.		
Which language does he prefer for an interview?		
☐ English ☐ Spanish ☐ Other		
* If you need more room to list brothers or sons,	nlease use a	nother sheet

Returned by: FIELD(PTFNAME) FIELD(PTMNAME) FIELD(PTLNAME)

FIELD(prproject), FIELD(pethnic1), FIELD(PTID)

Thank you for your time. Yo prostate cancer.	ur participation will	make a difference in	n the fight against
Please take a few more minu	tes to answer the fol	lowing question:	
May we contact you again for	a future study?	□ Yes	□ No
Check this box if you do n	ot wish to participat	e in this study.	
Please tell us why not:			

Chank You

Roshan Bastani, Ph.D.

Division of Cancer Prevention and Control Research
Jonsson Comprehensive Cancer Center
University of California, Los Angeles
650 Charles Young Drive
A2-125 CHS, Box 956900
Los Angeles, CA 90096-6900

Returned by: FIELD(PTFNAME) FIELD(PTMNAME) FIELD(PTLNAME)

FIELD(prproject), FIELD(pethnic1), FIELD(PTID)

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DIVISION OF CANCER PREVENTION AND CONTROL RESEARCH
DEPARTMENT OF HEALTH SERVICES
SCHOOL OF PUBLIC HEALTH
ROOM A2-125 CHS
BOX 956900
LOS ANGELES, CALIFORNIA 90095-6900
(310) 825-3181 FAX (310) 206-3566

Patricia A. Ganz, M.D. Director (310) 206-1404

Roshan Bastani, Ph.D. Associate Director (310) 206-9266

17 de septiembre de 1999

FIELD(ptfname) FIELD(ptlname)
FIELD(paddres1)
FIELD(ptcity), FIELD(ptstate) FIELD(ptzip)

Estimado Sr. FIELD(ptlname):

Necesitamos su ayuda para luchar contra el cáncer de la próstata. Le invitamos a que se una al estudio del cáncer de la próstata que se esta llevando acabo en la División para la Prevención y Control del Cáncer en UCLA. Recibimos su nombre del Programa de Vigilancia de Cáncer del Condado de Los Angeles porque usted ha tenido cáncer de la próstata.

Como usted podrá saber, familiares cercanos de personas que han tenido cáncer de la próstata son mas propensos a desarrollar cáncer de la próstata. Nos gustaría hablar con sus familiares cercanos acerca de lo que saben y sienten sobre el cáncer de la próstata, aunque ellos no tengan cáncer de la próstata.

Hemos incluido un formulario que nos gustaría que llenara y regresara. Por favor tome unos minutos para ver los materiales adjunto mientras decide participar. Su participación es completamente voluntaria. Su decisión no afectara los servicios que reciba de su doctor o del Programa de Vigilancia de Cáncer del Condado de Los Angeles.

Esperamos que escoja ser parte de este estudio. Usted puede hacer una diferencia en la lucha contra el cáncer de la próstata. Gracias por su tiempo e interés.

Sinceramente,

Roshan Bastani, Ph.D.

Dr. C. Rastan

Nilsa Gallardo, Psy.D.

Informacion Familiar



Familias Saludables



Programa para la Prevención del Cáncer de la Próstata
Universidad de California, Los Angeles

Por favor tome unos minutos para darnos información sobre su padre y hermano(s) e hijo(s) adultos. **SU PADRE:** Nombre Edad Domicilio Cuidad Teléfono ¿Sabe él que usted tuvo cáncer de la próstata? Sí No ¿Le pidió permiso a él antes de darnos su nombre? Sí No ¿Podemos comunicarnos con él para este estudio? Sí No Si **no**, por favor diganos por que no. ¿En que idioma prefiere él la entrevista? Ingles \Box Español Otro **HERMANO:** Nombre Edad Domicilio Cuidad Estado Zona Postal Teléfono ¿Sabe él que usted tuvo cáncer de la próstata? Sí No ¿Le pidió permiso a él antes de darnos su nombre? Sí No ¿Podemos comunicarnos con él para este estudio? Sí No Si **no**, por favor diganos por que no. ¿En que idioma prefiere él la entrevista? Ingles Español Otro

HERMANO:*				
	Nombre			Edad
	Domicilio			
	Cuidad	Estado	Zona Postal	
	() Teléfono			
¿Le pidió permiso	tuvo cáncer de la pra a él antes de darnos carnos con él para es	su nombre?	□ Sí□ Sí□ Sí	□ No □ No □ No
Si no, por favor di	ganos por que no			
¿En que idioma pro	efiere él la entrevista	?		
□ Ingles □ E	Español 🗆 O	tro		
ніјо:				
(ADULTO)	Nombre			Edad
	Domicilio			
	Cuidad () Teléfono	Estado	Zona Postal	
¿Le pidió permiso	tuvo cáncer de la pr a él antes de darnos carnos con él para es	su nombre?	□ Sí □ Sí □ Sí	□ No□ No□ No
Si no, por favor di	ganos por que no			
¿En que idioma pr	efiere él la entrevista	?		
□ Ingles □ H	Español 🗖 O	tro		

HIJO:						
(ADULTO)	Nombre				Edac	
	Domicilio		,			
	Cuidad	Estado	Z	ona Postal		
	Teléfono					
¿Le pidió permiso ¿Podemos comuni	l tuvo cáncer de la pr a él antes de darnos carnos con él para es	su nombre? ste estudio?		Sí Sí Sí		No No No
Si no , por favor d	iganos por que no			· · · · · · · · · · · · · · · · · · ·		
¿En que idioma pr	efiere él la entrevista	?				
□ Ingles □ H	Español 🗖 O	tro		···		
ніјо:						
/ A == == == = = :						
(ADULTO)*	Nombre				Edad	
(ADULTO)*	Nombre Domicilio				Edad	
(ADULTO)*		Estado	Z	ona Postal	Edad	
(ADULTO)*	Domicilio	Estado	Z	ona Postal	Edad	
¿Sabe él que usted	Domicilio Cuidad () Teléfono tuvo cáncer de la pro	óstata?	z	Sí	Edad	No
¿Sabe él que usted ¿Le pidió permiso	Domicilio Cuidad () Teléfono	óstata? su nombre?			0	
¿Sabe él que usted ¿Le pidió permiso ¿Podemos comunic	Domicilio Cuidad () Teléfono tuvo cáncer de la pro a él antes de darnos	óstata? su nombre? te estudio?	0	Sí Sí	0	No No
¿Sabe él que usted ¿Le pidió permiso ¿Podemos comunio Si no , por favor di	Cuidad () Teléfono tuvo cáncer de la proa él antes de darnos carnos con él para es	óstata? su nombre? te estudio?	0	Sí Sí	0	No No
¿Sabe él que usted ¿Le pidió permiso ¿Podemos comunio Si no , por favor di ¿En que idioma pro	Cuidad () Teléfono tuvo cáncer de la proa él antes de darnos carnos con él para es ganos por que no	óstata? su nombre? te estudio?	0	Sí Sí	0	No No
¿Sabe él que usted ¿Le pidió permiso ¿Podemos comunidos si no, por favor di ¿En que idioma pro l'Ingles	Cuidad () Teléfono tuvo cáncer de la proa él antes de darnos carnos con él para es ganos por que no	óstata? su nombre? te estudio? ?	0 0	Sí Sí Sí	0 0 0	No No No

FIELD(PrProject), FIELD(pethnic1), FIELD(ptid)

Gracias por su tiempo. Su participación hará una diferencia en la batalla contra el cáncer de la próstata.
Por favor tome unos minutos más para contestar la próxima pregunta:
¿Nos podemos comunicar con usted en el futuro para otro estudio? Sí No
☐ Si no desea participar en este estudio, marque la cajita.
Por favor diganos porque no desea participar:

Gracias

Roshan Bastani, Ph.D.

División para la Prevención y Control del Cáncer
Jonsson Centro Comprensivo del Cáncer
Universidad de California, Los Angeles

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SANTA BARBARA · SANTA CRUZ

April 6, 1999

FIELD(fname) FIELD(lname)
FIELD(address)
FIELD(city), FIELD(state) FIELD(zip)

DIVISION OF CANCER PREVENTION AND CONTROL RESEARCH
DEPARTMENT OF HEALTH SERVICES
SCHOOL OF PUBLIC HEALTH
ROOM A2-125 CHS
BOX 956900
LOS ANGELES, CALIFORNIA 90095-6900
(310) 825-3181 FAX (310) 206-3566

Patricia A. Ganz, M.D. Director (310) 206-1404

Roshan Bastani, Ph.D. Associate Director (310) 206-9266

Dear Mr. FIELD(Iname):

We need your help to fight prostate cancer. We invite you to join the UCLA Division of Cancer Prevention and Control in a research study on prostate cancer. Your name, address and telephone number were given to us by your (father, brother, son)(first and last name) who has had prostate cancer. He thought you might be interested in participating in this study.

As you may know, close relatives of people who have had prostate cancer are more likely to get prostate cancer. We would like to find out what you know about prostate cancer and catching it early. Your time and answers to our questions can really make a difference. You can help us develop programs and materials that can save lives and help people live longer.

We have included a form that we would like you to fill out and return. Please take a few minutes to look at the enclosed material as you make your choice to be involved. Your participation is completely voluntary, but we hope you choose to be part of this study. You can make a difference in the fight against prostate cancer.

Thank you for your time and caring.

Sincerely,

Roshan Bastani, Ph.D.

Dr. R. Bartani

Division of Cancer Prevention and Control Research Jonsson Comprehensive Cancer Center at UCLA

Hspc # G96-01-005-03A

Thank you...

for agreeing to participate in the UCLA Healthy Families Research Study

Please verify the following information:					
Ad Cit	me: Idress: cy: State: Zip Code: Age: ome Phone: () Work Phone: ()				
I	Please take a moment to answer the following:				
1.	. Have you ever been diagnosed with Prostate cancer? Yes No If Yes, when were you diagnosed (give month and year)				
 Indicate the best times (in general) to reach you for the telephone interview. (For example, mornings before 9:30 am, afternoons, or evenings after 4:30 pm.) 					
3.	In which language would you prefer the telephone interview? English Spanish Other				
4.	. Check this box if you do NOT want us to call you.				
W	e look forward to talking with you soon.				
	Roshan Bastani, Ph.D. UCLA Division of Cancer Prevention and Control Research Jonsson Comprehensive Cancer Center 650 Charles Young Drive South Box 956900 A2-125 CHS Los Angeles, CA 90095-6900				

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SANTA BARBARA · SANTA CRUZ

DIVISION OF CANCER PREVENTION AND CONTROL RESEARCH DEPARTMENT OF HEALTH SERVICES SCHOOL OF PUBLIC HEALTH ROOM A2-125 CHS BOX 956900 LOS ANGELES, CALIFORNIA 90095-6900

> Patricia A. Ganz, M.D. Director (310) 206-1404

> Roshan Bastani, Ph.D. Associate Director (310) 206-9266

20 de septiembre de 1999 (310) 825-3181 FAX (310) 206-3566

FIELD(fname) FIELD(mname) FIELD(lname) FIELD(address) FIELD(city), FIELD(state) FIELD(zip)

Estimado Sra. FIELD(lname):

estudio del cáncer de la próstata que se esta llevando acabo en la División para la Prevención y Control del Cáncer en UCLA. Recibimos su nombre, domicilio y numero de teléfono de su [HIJO, HERMANO, PAPÁ,] quien ha tenido cáncer de la próstata. El pensó que usted estaría interesado en participar en este estudio.

Necesitamos su ayuda para luchar contra el cáncer de la próstata. Le invitamos a que se una al

Como usted podrá saber, familiares cercanos de personas con historia del cáncer de la próstata son mas propensos a desarrollar cáncer de la próstata. Nos gustaría saber lo que usted sabe sobre el cáncer de la próstata y la detección temprana. Su tiempo y respuestas a nuestras preguntas pueden hacer una gran diferencia. Usted nos puede ayudar a desarrollar programas y materiales que pueden salvar vidas y ayudar a que personas tengan una vida duradera.

Hemos incluido un formulario que nos gustaría que llenara y regresara. Por favor tome unos minutos para leer la información adjunta mientras decide participar. Su participación es completamente voluntaria, pero esperamos que decida ser parte de este estudio. Usted puede hacer una diferencia en la lucha contra el cáncer de la próstata.

Gracias por su tiempo e interés.

Dr. R. Rastan

Sinceramente.

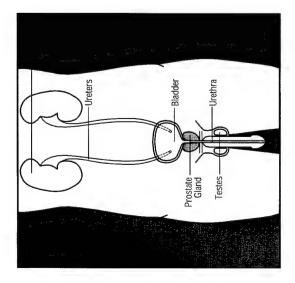
Roshan Bastani, Ph.D.

División para la Prevención y Control del Cáncer Jonsson Centro Comprensivo del Cáncer en UCLA Gracias...

por acceder a participar en el programa Familias Saludables de UCLA

Por favor de verificar la siguiente información:					
Nombre: Domicilio: Ciudad: Tel.(Domicilio):	Estado:	Zona Postal: Tel. (Trabajo)	Edad:		
Por favor tome un mom	nento para c	ontestar lo siguient	te:		
. ¿Ha sido alguna vez diagnosticado con cáncer la próstata? Si No Si fue así, cuando fue diagnosticado (de mes y ano)					
Indique el mejor tiempo (en general) para comunicarnos con usted para la entrevista telefónica. (Por ejemplo, en las mañanas antes de las 9:30 am, tardes, o noches después de las 4:30 pm.)					
¿En que idioma prefiere la entrevista telefónica? Ingles Español Otro					
4. Marque esta caja si NO c	quiere que le llas	memos.			
Esperamos hablar con usted pron	to.				
Jonsson C	n de la Prevenci Centro Compren 650 Charles Yo Box 956900	stani, Ph.D. ón y Control del Cáncer sivo del Cáncer en UCLA ung Drive South A2-125 CHS CA 90095-6900	A		

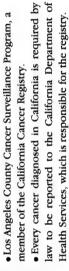
Early Detection



The prostate is a gland found only in men. It produces a thick fluid that forms part of the semen. The prostate is about the size of a walnut. It is located below the bladder. The prostate surrounds the upper part of the urethra, the tube that empties urine from the bladder.



Team conducting the Prostate Cancer Prevention Project. From left to right: Drs. David Huang, Roshan Bastani, Mark Litwin, Nilsa Gallardo, Clarence Bradford.

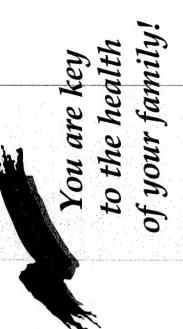


• Information on individuals with cancer can only be released for research purposes to qualified researchers who have obtained approval for the study from a federally approved Committee for the Protection of Research Subjects.

Jonsson Comprehensive Cancer Center

Division of Cancer Prevention and Control 650 Charles Young Drive South Room A2-125 CHS Box 956900 Los Angeles, CA 90095-6900







UCLA

PROJECT



"You are key to the health of your family"

A note to you:

Lou can help in the fight against prostate cancer by joining in the Healthy Families research study. This study aims to catch prostate cancer early and save lives.

Why am I key?

You are key because you have had prostate cancer.

The men in your family are more likely to get prostate cancer than men who have no prostate cancer in their family. The Healthy Families Project wants to develop new programs to help fight prostate cancer in close family members. We need your help in contacting your father, brothers and adult sons, even if they do not have prostate



What will I need to do?

All you need to do is:

- 1. Fill out the attached Family Information Form.
- Return the form in the enclosed stamped envelope.

What will my family members need to do?

to ask them to participate in telephone interviews. If they agree, we will ask them about what they know and how they feel about prostate cancer and its early detection.

What will happen to the information my family members provide?

W programs to fight prostate cancer in close family members.

Do I need to participate?

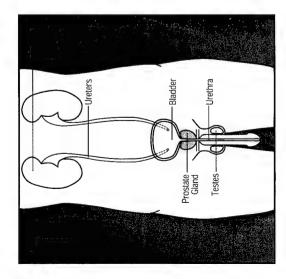
family's health. Your participation is voluntary and all information will be confidential. There is no cost to you to participate. Your choice to take part will not affect the services you receive from your doctor or the Los Angeles County Cancer Surveillance Program. If you do not want us to call you or your family members, just mark the box on the form that says "I do not want to participate" and return it in the enclosed envelope.

Who can I call if I have questions?

V ou may call us toll-free at (877) 278-8506. We will be happy to answer your questions.

"You are key to the health of your family"

Early Detection



The prostate is a gland found only in men. It produces a thick fluid that forms part of the semen. The prostate is about the size of a walnut. It is located below the bladder. The prostate surrounds the upper part of the urethra, the tube that empties urine from the bladder.

 Every cancer diagnosed in California is required by law to be reported to the California Department of

Health Services, which is responsible for the registry.

• Information on individuals with cancer can only be

study from a federally approved Committee for the

Protection of Research Subjects.

released for research purposes to qualified researchers who have obtained approval for the

Los Angeles County Cancer Surveillance Program, a

member of the California Cancer Registry.



You are key to the health

of your family!

Team conducting the Prostate Cancer Prevention Project. From left to right: Drs. David Huang, Roshan Bastani, Mark Litwin, Nilsa Gallardo, Clarence Bradford.



UCLA HEALTHY | A | W

PROJECT

Jonsson Comprehensive Cancer Center
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شر غ <u>در</u> غ

Los Angeles, CA 90095-6900

Box 956900

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What will happen to the information my family members provide?

W e will use it to develop new programs to fight prostate cancer in close family members.

Do I need to participate?

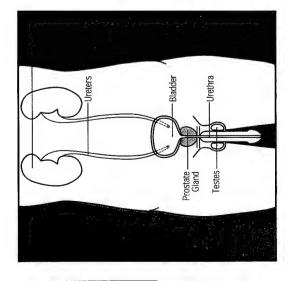
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Who can I call if I have questions?

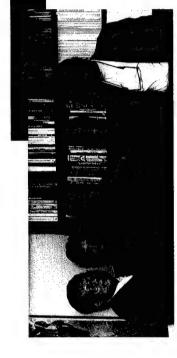
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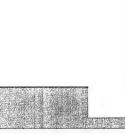
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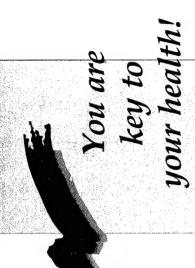
Team conducting the Prostate Cancer Prevention Project. From left to right: Drs. David Huang, Roshan Bastani, Mark Litwin, Nilsa Gallardo, Clarence Bradford.



Please be aware that, since they are providing funding for this study, representatives from the U.S. Army Medical Research and Material Command (and, where applicable, the Food and Drug Administration) may inspect the records of the research in their duty to protect human subjects in research.

Jonsson Comprehensive Cancer Center Division of Cancer Prevention and Control 650 Charles Young Drive South Room A2-125 CHS Box 956900 Los Angeles, CA 90095-6900

7 2





UCLA

PROJECT





"You are key to your health"

A note to you:

Vou can help in the fight against prostate cancer by joining in the Healthy Families research study. This study aims to catch prostate cancer early and save lives.

Why am I key?

You are key because someone in your family has had prostate cancer.

L higher risk of getting prostate cancer than men who have no prostate cancer in their family. We at the **Healthy Families** Project are committed to recruiting Asian men such as yourself. This is so that we can get information on your special needs and concerns. The information you provide will be



used to develop new programs to fight prostate cancer in close family members.

What will I need to do?

All you need to do is:

ake part in a 20 minute telephone interview. We will ask you questions about what you know and how you feel about prostate cancer and its early detection.

Do I need to participate?

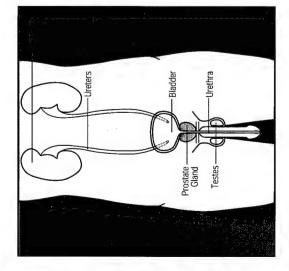
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V ou may call us toll-free at (877) 278-8506. We will be happy to answer your questions. If you have more questions, thoughts, or concerns, you can write the Office for Protection of Research Subjects, 2107 Peter V. Ueberroth Building, Box 951694, Los Angeles, CA 90095, (310) 825-8714.

"You are key to your health"

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Team conducting the Prostate Cancer Prevention Project. From left to right: Drs. David Huang, Roshan Bastani, Mark Litwin, Nilsa Gallardo, Clarence Bradford.



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Division of Cancer Prevention and Control
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used to develop new programs to fight prostate cancer in close family members.

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Do I need to participate?

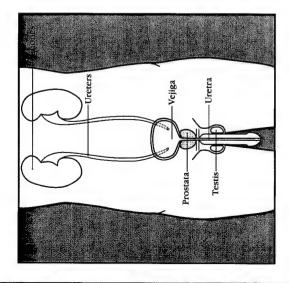
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"You are key to your health"

Detección Temprana



La prostata es una glandula que se encuentra solamente en los hombres. Ella produce un liquido espeso que forma parte del semen. La prostata es mas o menos del tamaño de una nuez. Esta localizada bajo la vejiga. La prostata rodea la parte superior de la uretra, el tubo que vacia la orina de la vejiga.



Equipo conduciendo el Programa para la Prevención del Cáncer de la Prostata. De izquierda a derecha: Drs. David Huang, Roshan Bastani, Mark Litwin, Nilsa Gallardo, Clarence Bradford.



Favor este consciente que, por que han dado fondos para este estudio, representantes del comando de investigación medico y de materiales de las fuerzas armadas de los Estados Unidos (y donde es pertinente, la Administracion de Alimentos y Drogas) pueden inspecciónar los expedientes de la investigación en su obligación a proteger sujectos humanos en investigaciónes.

Jonsson Comprehensive Cancer Center
Division of Cancer Prevention and Control
650 Charles Young Drive South

As a roung Drive South Room A2-125 CHS

Box 956900

Los Angeles, CA 90095-6900



"Usted es clave para su salud"

Una nota para usted:

sted puede ayudar en la lucha contra el cáncer de la prostata uniendose al estudio de investigación Familias Saludables. Este estudio aspira detectar cáncer de la prostata temprano y asi salvar vidas.

¿Por que soy yo clave?

Usted es clave porque alguien en su familia ha tenido cáncer de la prostata.

mas alto riesgo de desarrollar cáncer de la prostata que personas que no tienen cáncer de la prostata en su familia. Nosotros en el Programa de Familias Saludables estamos comprometidos a reclutar hombres hispanos como usted para obtener información en especial sobre sus necesidades y preocupaciones. La información que



usted proporcione sera usada para desarrollar nuevos programas para combatir el cáncer de la prostata en familiares cercanos.

¿Que tendré que hacer?

Lo unico que usted tiene que hacer es:

articipar en una entrevista telefónica de 20 minutos. Le haremos preguntas acerca de lo que sabe y siente sobre el cáncer de la prostata y su detección temprana.

¿Tengo que participar?

No pero esperamos que lo haga por su salud y la de su familia. Su participación es voluntaria y toda la información sera confidencial. No hay ningun costo para participar. Si usted no quiere participar por favor marque la caja que dice "Yo no quiero participar" en el formulario y regreselo en el sobre adjunto. Usted puede dejar de participar en el estudio en cualquier momento.

¿A quien puedo llamar si tengo preguntas?

sted puede llamarnos gratis al numero (877) 278-8506. Estaremos encantado/as de contestar sus preguntas. Si tiene mas preguntas, opiniones, o inquietudes, usted puede escribir a la Oficina de Protección a Sujetos de Investigación, 2107 Peter V. Ueberroth Building, Box 951694, Los Angeles, CA 90095, (310) 825-8714.

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INTRODUCTION/VERBAL CONSENT

NOTE FOR 1st PARAGRAPH	l:
*IF RID = "2" CHOOSE SON	, IF RID = "4" CHOOSE BROTHER, IF RID = "6" CHOOSE
FATHER	

*INSERT PTFNAME AND PTLNAME IN SECOND BLANK

Hello, my name is	_, and I am calling from the UCLA Healthy Families
Prostate Health Project to conduct a health	h survey. We got your name from your [BROTHER
FATHER, SON] Did he	ne talk to you about this study?

- 1 YES → Good. Let me remind you...
- 0 NO → Let me explain that...

This project is being conducted by the UCLA Cancer Center. We are doing telephone interviews with close relatives of prostate cancer patients. The interview will take about 20 minutes and asks your opinion and belief about cancer, your health practices and some background information about you. Your answers will help us develop programs to educate people about early detection of prostate cancer.

We recently sent you some materials explaining the study. Did you receive it? Let me assure you that all your answers will be confidential. All information will be used only for the purposes of this study. No information which identifies you will be released without your consent. Your participation is completely voluntary and you can stop the interview at any time.

If you would like, I can give you the telephone number for Dr. Bastani, who is conducting this project, so that you can contact her if you have any questions now or in the future. [DR. BASTANI'S NUMBER IS: 310.206.9266; RESPONDENTS MAY CALL COLLECT]

I can also give you the Vice Chancellor's [310.825.8714] and the Human Subjects Protection Committee number [310.825.7122] at UCLA.

NOTE: FOR Q0A, IF ANSWER IS "NO" SURVEY WILL BE TERMINATED. GO TO SUMMARY SCREEN BEFORE RETURNING TO LOG SHEET. ALSO, ASSIGN CODE "7" FOR SRVSTAT1 AND CODE "7" TO SRVTERM1 IN RELATIVE TRACKING DATABASE

Q0A Would you be willing to answer some questions?

- 1 YES → CONTINUE
- NO → I understand your decision. If you do have questions about prostate cancer, early detection and treatment, you can call the Cancer Information Service. Would you like their toll free number? (1-800-4-CANCER). If you change your mind about participating, please feel free to call us toll-free at 1-877-278-8506. Thank you for your time. Good bye.

Q0B Is this a good time for you?
1 YES → CONTINUE 0 NO → When may I call you again? Let me assure you that there is no right or wrong answer. We are interested only in finding out what you feel and what you believe about cancer and other issues.
NOTE FOR Q001: * ASK IF PLET1STA = "1" AND RAGE <> "" OTHERWISE GO TO Q003 * IF RID = "2", CHOOSE SON; IF RID = "4" CHOOSE BROTHER; IF RID = "6" CHOOSE FATHER *INSERT PTFNAME AND PTLNAME IN FIRST BLANK * INSERT RAGE IN SECOND BLANK ***********************************
Q001. Let me begin by verifying your age. Your [BROTHER, FATHER, SON] told us that you are years old. Is that correct?
1 YES (SKIP TO → Q004) W. DK 0 NO X. RF
************* NOTE FOR Q002: * IF Q002 > 40 OR Q002 < 75, GO TO Q004 * IF Q002 < 40 OR Q002 > 75 GO TO Q003w **********************************
Q002. Would you mind verifying your age? (RAGE)
FOR Q003: IF CASE DID NOT RETURN MATERIALS, OR DID NOT GIVE US THE AGE(S), PLEASE SAY, ************* NOTE FOR Q003: * IF Q003 > 40 OR Q003 < 75, GO TO Q004 * IF Q003 < 40 OR Q003 > 75 GO TO Q003w * IF RID = "2", CHOOSE SON; IF RID = "4" CHOOSE BROTHER; IF RID = "6" CHOOSE FATHER *INSERT PTFNAME IN BLANK ***********************************
Q003. I did not get your age from your [BROTHER, FATHER, SON]. Would you mind telling me how old you are please?(RAGE)
NOTE: FOR Q003 IF PARTICIPANT IS UNDER 40 YEARS OF AGE OR OVER 75 YEARS OF AGE, THEY ARE NOT ABLE TO PARTICIPATE. Please say,]
Q003w. "I appreciate your willingness to participate at this time. Unfortunately, the telephone survey is conducted only with those who are between 40 and 75 years of age. Do you have any questions for me before we end this call? Thank you for your time. Good-bye."

NOTE: AFTER READING Q003w, INSERT '0' IN RELATIVE TRACKING VARIABLE "RELIG2" ALSO INSERT "7" IN SRVSTAT1 AND "7" IN SRVTERM11 GO TO SUMMARY SCREEN BEFORE RETURNING TO LOG SHEET Q004. I'd like to ask you some questions about your health. Has a doctor ever told you that you have or had any type of cancer? 1 YES W. DK (SKIP TO → Q007) 0 NO (SKIP TO → Q007) X. RF (SKIP TO → Q007) NOTE: IF Q005a, or Q005b, or Q005c = '2', SUBJECT IS INELIGIBLE FOR STUDY. GO TO Q0006 AND END CALL. [MAKE NOTE IN RELATIVE TRACKING DATABASE VARIABLE RELIG2 = "2", SRVSTAT1 = "7", **SRVTERM1 = "7"**] GO TO SUMMARY SHEET BEFORE RETURNING TO LOG SHEET Q005. What type of cancer? Q005a _____, Q005b ____, Q005c ____ 1. Colon (GO TO -> Q007) 2. Prostate 5. Lung (GO TO -> Q007) V. Other (Q005V) (GO TO -> Q007) W. DK (GO TO -> Q007) X. RF (GO TO -> Q007) Q006 "I'm sorry to hear that. I appreciate your willingness to participate in this study. Unfortunately, the telephone survey is conducted only with those who have not had prostate cancer. Do you have any questions for me before we end this call? Thank you for your time. Good-bye." NOTE: AFTER READING Q006, INSERT '2' IN RELATIVE TRACKING VARIABLE "RELIG2" ALSO INSERT "7" IN SRVSTAT1 AND "8" IN SRVTERM1] GO TO SUMMARY SCREEN BEFORE RETURNING TO LOG SHEET ***** Q007. In general, would you say your health is ... Poor Excellent W. DK 2. Very good 3. Good X. RF 4. Fair Q008. Has a doctor ever told you that you have an enlarged or swollen prostate? This is also known as benign prostatic hyperplasia (BPH)? W. DK 1. YES 0. NO X RF

Prostate.itempool. collective.wpd

Q009. Has a doctor ever told you that you have any other serious health problem?

 YES (Specify: _ NO 		_)(009s)	W. DK X RF
			ROTHER; IF RID = "6" CHOOSE FATHER FTER ASKING Q010, SKIP TO Q012.
Q010. Now I'd like to	ask you some que	estions about	t other members of your family and <u>their</u> health.
Let's start with your [FA from being diagnosed v	THER, BROTHER, with prostate cancer	SON] , has he been	who referred you to this study. Aside diagnosed with any other type of cancer?
1. YES 0 NO (SKIP T	O → Q011)	W. DK X RF	(SKIP TO → Q011) (SKIP TO → Q011)
What type of cancer?	At what age was h	e diagnosed?	
(Q010a1) (Q010a2)	(Q010b1) (Q010b2)		
 Colon Prostate Breast Lung 			
V. Other W. DK X. RF			
Q011. Has your father	been diagnosed wi	th cancer?	
1 YES 0. NO (SKIP TO	→ Q012) W	. DK (SKIP RF (SKIPT	TO → Q012) O → Q012)
What type of cancer?	At what age was h	e diagnosed?	Is your father(1) related to you by "blood" OR (2) your stepfather?
(Q011a1) (Q011a2)	(Q011b1) (Q011b2)		(Q011c)
 Colon Prostate Breast Lung 			
V. Other			
W. DK X. RF			
Q012 Has your moth	er been diagnosed	with cancer?	

1 YES 0 NO (SKIP TO -		W. DK (SKIP X RF (SKIP	
What type of cancer?	At what age was she dia	ignosed?	Is your mother (1) related to you by "blood OR (2) your stepmother?
(Q012a1) (Q012a2)	(Q012b1) (Q012b2)		(Q012c)
 Colon Breast Cervical Lung Ovarian Endometria 	ıl		
V. Other			
W. DK X. RF			
NOTE FOR Q013: ONLY DISPLAY THE C	CORRESPONDING NUM	IBER OF BRO	THER SECTIONS INDICATED IN Q013a
Q013. Have any of you	ur brothers been diagnos	sed with cancer	?
1. YES -> How m 0. NO (SKIP TO	any?(Q013a) → Q014)		
W. DK (SKIP TO X. RF (SKIP TO			
BROTHER 1:			
What type of cancer?	At what age was he diag	gnosed?	
(Q013a1) (Q013a2)	(Q013b1) (Q013b2)		
 Colon Prostate Breast Lung 			
V. Other W. DK X. RF			
Q013c. Is your brother	·		
2 your half brot	u by "blood" (GO TO –>Q ther ther (GO TO –>Q013a3)	013a3)	

Q013d Is your half brother from your mother's or father's side?		
1 MOTHER 2 FATHER		
W DK X RF		
BROTHER 2:		
What type of cancer? At	what age was he diagnosed?	
(Q013a3) (Q0 (Q013a4) (Q0	013b3) 013b4)	
 Colon Prostate Breast Lung 		
V. Other W. DK X. RF		
Q013e Is your brother		
2 your half brother	"blood" (GO TO ->Q013a5) (GO TO ->Q013a5)	
Q013f Is your half brother	from your mother's or father's side?	
1 MOTHER 2 FATHER		
W DK X RF		
BROTHER 3:		
What type of cancer? At	what age was he diagnosed?	
(Q013a5) (Q (Q013a6) (Q	013b5) 013b6)	
 Colon Prostate Breast Lung 		
V. Other W. DK X. RF		
Q013g Is your brother		
1 related to you by 2 your half brother	"blood" (GO TO ->Q014)	

	3 your step brother (GO TO ->Q014)
Q013h	Is your half brother from your mother's or father's side?
	1 MOTHER 2 FATHER
	W DK X RF
	******* FOR Q014: DISPLAY THE CORRESPONDING NUMBER OF SISTER SECTIONS INDICATED IN Q014a
*****	· 表表表表
Q014.	Have any of your sisters been diagnosed with cancer?
1. 0.	YES -> How many?(Q014a) NO (SKIP TO → Q015)
	DK (SKIP TO → Q015) RF (SKIP TO → Q015)
SISTER	R 1:
What ty	pe of cancer? At what age was she diagnosed?
(Q014a (Q014a	1) (Q014b1) 2) (Q014b2)
	 Colon Breast Cervical Lung Ovarian Endometrial
	V. Other W. DK X. RF
Q014c	Is your sister
	1 related to you by "blood" (GO TO ->Q014a3) 2 your half sister 3 your step sister (GO TO ->Q014a3)
Q014d	Is your half sister from your mother's or father's side?
	1 MOTHER 2 FATHER
	W DK X RF

SISTER	? 2 :	
What ty	pe of cancer?	At what age was she diagnosed?
(Q014a3 (Q014a4	3) 4)	(Q014b3) (Q014b4)
	 Colon Breast Cervical Lung Ovarian Endometria 	!
	V. Other W. DK X. RF	
Q014e	ls your sister	
	2 your half siste	ı by "blood" (GO TO>Q014a5) er er (GO TO>Q014a5)
Q014f	Is your half sist	er from your mother's or father's side?
	1 MOTHER 2 FATHER	
	W DK X RF	
SISTER	₹3:	
What ty	pe of cancer?	At what age was she diagnosed?
(Q014a5) (Q014b5) (Q014a6) (Q014b6)		(Q014b5) (Q014b6)
	 Colon Breast Cervical Lung Ovarian Endometria 	ıl
	V. Other W. DK X. RF	
Q014g	Is your sister	
	1 related to you 2 your half siste	u by "blood" (GO TO ->Q015) er

3 your step sister (GO TO ->Q015)
Q014h Is your half sister from your mother's or father's side?
1 MOTHER 2 FATHER
W DK X RF
NOTE FOR Q015: ONLY DISPLAY THE CORRESPONDING NUMBER OF SON SECTIONS INDICATED IN Q015a

Q015. Have any of your sons been diagnosed with cancer?
 YES -> How many?(Q015a) NO (SKIP TO → Q016)
W. DK (SKIP TO → Q016) X. RF (SKIP TO → Q016)
SON 1:
What type of cancer? At what age was he diagnosed?
(Q015a1) (Q015b1) (Q015a2) (Q015b2)
 Colon Prostate Breast Lung
V. Other W. DK X. RF
Q015c Is your son
1 related to you by "blood" 2 your adopted son 3 your step son
SON 2:
What type of cancer? At what age was he diagnosed?
(Q015a3) (Q015b3) (Q015a4) (Q015b4)
Colon Prostate

3. Breast5. Lung
V. Other W. DK X. RF
Q015d Is your son
1 related to you by "blood" 2 your adopted son 3 your step son
SON 3:
What type of cancer? At what age was he diagnosed?
(Q015a5) (Q015b5) (Q015a6) (Q015b6)
 Colon Prostate Breast Lung
V. Other W. DK X. RF
Q015e Is your son
1 related to you by "blood" 2 your adopted son 3 your step son

Q016. Have any of your daughters been diagnosed with cancer?
 YES -> How many? (Q016a) NO (SKIP TO → Q017)
W. DK (SKIP TO → Q017) X. RF (SKIP TO → Q017)
DAUGHTER 1:
What type of cancer? At what age was she diagnosed?
(Q016a1) (Q016b1) (Q016a2) (Q016b2)

 Colon Breast Cervical Lung Ovarian Endometrial
V. Other W. DK X. RF
Q016c Is your daughter
1 related to you by "blood"2 your adopted daughter3 your step daughter
DAUGHTER 2:
What type of cancer? At what age was she diagnosed?
(Q016a3) (Q016b3) (Q016a4) (Q016b4)
 Colon Breast Cervical Lung Ovarian Endometrial
V. Other W. DK X. RF
Q016d Is your daughter
1 related to you by "blood" 2 your adopted daughter 3 your step daughter
DAUGHTER 3:
What type of cancer? At what age was she diagnosed?
(Q016a5) (Q016b5) (Q016a6) (Q016b6)
 Colon Breast Cervical Lung Ovarian Endometrial
V. Other W. DK

X. RF	
Q016e Is your daughte	r
1 related to you 2 your adopted 3 your step dau	daughter

NOTE FOR Q017: ONLY DISPLAY THE C	CORRESPONDING NUMBER OF GRANDFATHER SECTIONS INDICATED IN Q017a

Q017. Have any of you	ur grandfathers been diagnosed with cancer?
1. YES -> How m 0. NO (SKIP TO -	
W. DK (SKIP TO X. RF (SKIP TO	
GRANDFATHER 1:	
What type of cancer?	At what age was he diagnosed?
(Q017a1) (Q017a2)	(Q017b1) (Q017b2)
 Colon Prostate Breast Lung 	
V. Other W. DK X. RF	
Q017c. Is this your ma	ternal or paternal grandfather?
1 MATERNAL 2 PATERNAL	
GRANDFATHER 2:	
What type of cancer?	At what age was he diagnosed?
(Q017a3) (Q017a4)	(Q017b3) (Q017b4)
 Colon Prostate Breast Lung 	

V. Other W. DK X. RF
Q017d. Is this your maternal or paternal grandfather?
1 MATERNAL 2 PATERNAL
NOTE FOR Q018: ONLY DISPLAY THE CORRESPONDING NUMBER OF SISTER SECTIONS INDICATED IN Q018

Q018. Have any of your grandmothers been diagnosed with cancer?
1. YES -> How many?(Q018a) 0. NO (SKIP TO → Q019)
W. DK (SKIP TO → Q019) X. RF (SKIP TO → Q019)
GRANDMOTHER 1:
What type of cancer? At what age was she diagnosed?
(Q018a1) (Q018b1) (Q018a2) (Q018b2)
 Colon Breast Cervical Lung Ovarian Endometrial V. Other
W. DK X. RF
Q018c. Is this your maternal or paternal grandmother? 1 MATERNAL 2 PATERNAL
GRANDMOTHER 2:
What type of cancer? At what age was she diagnosed?
(Q018a3) (Q018b3) (Q018a4) (Q018b4)
 Colon Breast Cervical

5. Lung6. Ovarian7. Endometrial						
V. Other W. DK X. RF						
Q018d. Is this your maternal or patern	nal grandmother?					
1 MATERNAL 2 PATERNAL						
Q019. Is there anybody else in your fa	mily who has been diagnosed with cancer?					
 YES NO (SKIP TO → Q021) 	W. DK (SKIP TO → Q021) X RF (SKIP TO → Q021)					
Q020. WHO?						
(Q020a1)(Specify relationship)	(Q020b1) Type of cancer? (Q020c1) Age at diagnosis?					
(Q020a2)(Specify relationship)	(Q020b2) Type of cancer? (Q020c2) Age at diagnosis?					
(Q020a3) (Specify relationship)	(Q020b3) Type of cancer? (Q020c3) Age at diagnosis?					
 Niece Nephew Aunt Uncle Cousin Granddaughter Grandson Other W. DK X. RF 	 Colon Prostate Breast Cervical Lung Ovarian Endometrial Other DK X. RF 					
*********** NOTE FOR Q021: * IF RID = "2" CHOOSE SON; IF RID = "4" CHOOSE BROTHER; IF RID = "6" CHOOSE FATHER * INSERT PTFNAME IN BLANK ***********************************						
Q021. Now thinking back to your [father/brother/son] who had prostate cancer						
How would you rate his health today wit	h respect to his prostate cancer? Would you say it is					
1. Excellent 2. Very good						

Q022. Would you say his prostate cancer has
 Come back Not come back Spread to other parts of the body
W. DK X. RF
Q023. How did you see his treatment and recovery from prostate cancer? Would you say it was
 Very hard Somewhat hard Not hard
W. DK X. RF
Q024. Next, I'd like to ask about your feelings regarding prostate cancer.
How often do you think about your possibility of developing prostate cancer? Would you say
 Very often Once in a while Never DK RF
Q025. How worried are you that you may get prostate cancer? Would you say
 Very worried Somewhat worried Not worried DK RF
Q026. When you think about getting prostate cancer, how fearful are you? Would you say
 Very fearful Somewhat fearful Not fearful DK X RF
Q027. Would you say you are very nervous, somewhat nervous, or not nervous that you may get prostate cancer?
 VERY NERVOUS SOMEWHAT NERVOUS NOT NERVOUS

3. Good 4. Fair 5. Poor

W. DK X. RF

W. X.	DK RF		
Q028.	Do you think about get	ting prosta	ate cancer more often than you would like?
1. 0.	YES NO	W. DK X RF	
Q029. cance		u a few o	uestions about your health and some screening tests for prostate
How of	ften do you exercise? V	Vould you	say
1 2 3	Daily or more than 3 ti One to 3 times a week You do not exercise re	or	ek
	DK RF		
Q030.	During the past 12 mor	nths, have	you had a complete physical exam?
1. ` 0. I	YES NO		W. DK X RF
is inser	One test that is done to ted in the rectum to che rectal exam?	find pros eck for pro	tate cancer is the DRE or the "digital rectal exam" . For this test a finger blems with the prostate and large bowel. Have you ever heard of a
1. ` 0. I	YES NO		W. DK X RF
Q032.	Have you ever had a di	igital recta	al exam?
	YES NO (GO TO → Q034)		W. DK (GO TO → Q034) X RF (GO TO → Q034)
Q033.	When was your most re	ecent digit	al rectal exam? Was it?
2. 1 3. 3	Within the last 12 month 1- 2 years 3-5 years More than 5 years ago		W. DK X RF
Q034. This blo	In addition to the digital bood test is called a PSA	rectal ex or "prost	am, there is a special blood test used to check for prostate cancer. ate specific antigen" test. Have your ever heard of a PSA?
1. \ 0. l		W. DK X RF	
Q035.	Has your doctor (or nur	se) ever r	ecommended that you get a PSA blood test?
1. \ 0. N		W. DK X RF	
Q036.	Has your doctor (or nurs	se) ever r	ecommended that you not get a PSA blood test?

1. YES W. DK X RF 0. NO Q037. Have you ever had a PSA blood test? 1. YES

0. NO (SKIP TO → Q041)

W. DK (SKIP TO → Q041) X RF (SKIP TO → Q041)

Q038. How many PSAs have you had? Would you say ...?

1. One

W. DK

2. More than one

X RF

Q039. When was your most recent PSA? Was it ...?

1. Within the last 12 months

W. DK

2. 1- 2 years ago

X RF

3. 3-5 years ago

4. More than 5 years ago

Q040. Why did you have this PSA? Was it for a health problem or was it part of a routine screening check-up, when you did not have any problems?

- 1. BECAUSE OF A HEALTH PROBLEM
- 2. PART OF A ROUTINE SCREENING CHECK UP
- 3. OTHER (Specify) (Q040s)

W. DK

X RF

Q041. Have you ever been to a urologist? A urologist is a doctor who treats diseases of the kidneys, bladder, testicles, and prostate.

1. YES

W. DK

0. NO

X RF

Q042. A sigmoidoscopy or colonoscopy or "procto" is when a long bendable tube with a light on the end is inserted in the rectum and into the colon to check for problems. Have you ever heard of such an exam?

1. YES

W. DK

0. NO

X RF

Q043. Have you ever had a sigmoidoscopy or colonoscopy?

1. YES

W. DK (SKIP TO → Q045)

0. NO (SKIP TO → Q045)

X RF (SKIP TO → Q045)

Q044. When was your most recent sigmoidoscopy or colonoscopy? Was it ...?

1. Within the last 12 months

W. DK

2. 1-2 years ago

X RF

3. 3-5 years ago

4. More than 5 years ago

Q045. One test that is done to find colon cancer is the take home stool blood test. A take home stool blood test is when the stool is tested for blood. For this test, you place a small amount of your stool on a card every day for

3 days. You are usually asked not to eat red meat or certain fruits and vegetables during the test. Have you ever heard of a stool blood test?								
1. YES W. DK 0. NO X RF								
Q046. Have you ever had a take h	nome stool te	ested for	blood?					
 YES NO (GO TO → Q048) 			((GO T((GO TO					
Q047. When was your most recent test for blood in your stool? Was it?								
 Within the last 12 months 1-2 years ago 3-5 years ago More than 5 years ago 	W. Dł X RF	<						
Q048. Now, I'd like to ask you a answers are confidential.	few question	ons for s	statistica	ıl purpo	ses o	nly. Rem	nember tha	t your
What is the highest level in school	that you hav	ve comp	leted?					
NO SCHOOL 00 GRADE SCHOOL 01 HIGH SCHOOL 09	02	03 11	04 12	05	06	07	08	
COLLEGE 13		15	16					
POST COLLEGE 17		19	20					
W DK X RF								
Q049. Were you born in the Unite	d States?							
 YES (GO TO Q →Q052) NO 			W. DK X. RF					
Q050. In what country were you be W. DK	orn?		······································				-	
X. RF								
Q051. How long have you lived in	the U.S.?	Years:(0	Q051yy)			Months:((Q051mm)	
W. DK X. RF								
Q052. Do you consider yourself to	be?							
 Black/African-American Hispanic/Latino Asian/Asian-American White/Caucasian 								

5. 6. 7.	American Indian/Native American Pacific Islander (Hawaii, Guam, Samoa, other South Pacific Island) Mixed (Bi- or Multi-racial) specify(Q052s1)					
V.	Other: (specify)	(Q052s2)				
*****	•					
	FOR Q053: Q052 = "7"					
Q053.	Which race do you identify with most? _					
****	W. DK X. RF					
	FOR Q054: Q052 = "1"					
Q054.	Are you? 1. African American 2. West Indian (includes Caribbean Islands) 3. Cuban	4. South American 5. Puerto Rican V. Other W. DK X RF	_(Q054s)			
*****	•					
	FOR Q055: Q052 = "2"					
Q055.	Are you? 1. Mexican 2. Mexican American 3. Chicana 4. Central American 5. South American	6. Puerto Rican 7. Cuban V. Other W. DK X RF	(Q055s)			
	FOR Q056: Q052 = "3"					
Q056.	Are you? 1. Chinese 2. Japanese 3. Filipino 4. Vietnamese 5. Cambodian	6. Asian Indian7. Indonesian8. KoreanV. OtherW. DKX RF	(Q56s)			

Q057. Which of the following best describes your total household income, that is, the yearly income of all family members living with you? I don't need the exact amount...just a range. And remember, your answer is confidential. Would you say approximately ...?

1. Less than \$10,000 (0 - \$ 833/month) 2. \$10,000 - 24,000 (\$ 833 - \$2,000/month) 3. \$25,000 - 39,000 (\$2,083 - \$3,250/month)
4. \$40,000 - 54,000 (\$3,333 - \$4,500/month)
5. More than \$55,000 (More than \$4,583/month)
W. DK

Q058. Are you currently married or living with someone as married?

- 1. YES
- 0. NO
- X. RF

Q059. Now I'm going to read a list of things that some people think make a man more likely to get prostate cancer. For each one, please tell me whether or not you believe it can make a man more likely to get prostate cancer.

"Do you	believe	can make a man m	ore likely to get prost	ate car	icer?"		
				Yes No	Possibly	DK	RF
Q059a.	older age			.1	02	. w	X
Q059b.	certain things you eat			1	02.	w	X
Q059c.	too much stress			1	02.	w	X
Q059d.	having relatives with prosta	ate cancer		1	02.	w.	. X
Q059e.	drinking alcohol			1 .	. 02	w.	. X
Q059f.	not getting enough exercise	/physical activity		1 .	0 2	w.	X
•	exposure to harmful chemic the community			1.	0 2	W	x
Q059h.	too much sex	• • • • • • • • • • • • • • • • • • • •		1 .	02	: w	x
Q059i.	sitting on cold surfaces			1 .	0	2 W	۱ x
Q059j. la	ack of sex			1.	. 0	2 W	/×
Q060. W	/ho do you think gets prosta	te cancer most often	?				

- 1. Whites/Caucasians
- 2. Hispanics/Mexican Americans
- 3. Black/African Americans
- 4. Asian/Asian Americans

W. DK X RF

Q061. How likely is it that you will get prostate cancer during your lifetime? Would you say ...?

- 1. Very likely
- 2. Somewhat likely
- 3. Not very likely

W. DK X RF

Q062. The next set of questions have to do with your beliefs about screening for prostate cancer with the PSA blood test.

	YES	NO	NO OPINION	DK	RF
Before we talked today, did you know that you should get a digital rectal exam every year?	1	0	2	W	x
Q063. Did you know that you should have a PSA (prostate specific antigen) blood test every year?	1	0	2	W	X
•			_		
Q064 Are you fearful of getting tested?	1	0	2	W	X
Q065. Is getting a PSA blood test important to you?	1	0	2	w	x
Q066. Would it be difficult for you to pay for a PSA blood test?	1	0	2	W	X
Q067. Are you worried that screening will show you have prostate cancer?	1	0	2	W	Х
Q068. Can prostate cancer be cured if found early?	1	0	2	W	X
Q069. Did you know you needed the test?	1	0	2	W	X
Q070. Do you think prostate screening may cause sexual problems?	1	0	2	W	X
Q071. Would you have a problem getting transportation to the doctor?	1	0	2	w	X
Q072. Do you think you only need to get a PSA test if your doctor recommends it?	1	0	2	w	x

Q073. Would you say you agree or disagree with the following statements.

The benefits of getting a PSA blood test are greater than any inconvenience.

1. Agree

W. DK

	2. Disagree	X RF
Q074.	You only need a prosta	e cancer screening test when you have symptoms.
	 Agree Disagree 	W. DK X RF
Q075.	Going through prostate	screening is too much trouble for what you get out of it.
	 Agree Disagree 	W. DK X RF
Q076	. You do not have time to	get tested.
	 Agree Disagree 	W. DK X RF
Q077	. How many of your friend	s and family do you think get checked for prostate cancer? Would you say?
	Most	
	Few None	W. DK X RF
Q078	. Do you think there is an	ything you can do to prevent yourself from getting prostate cancer?
0.	YES NO MAYBE	W. DK X RF
Q079	. Have you ever discuss	ed your personal risk for getting prostate cancer with any friends or relatives?
	YES NO	W. DK X RF
Q080	. Have you ever discusse	d your personal risk for getting prostate cancer with your doctor?
	YES NO	W. DK X RF
Q081	. I'd like to ask you som	e questions about your insurance.
Do yo	ou have Medicare?	
	YES NO	W. DK X RF
Q082	. Do you have Medicaid/l	Medical?
	YES NO	W. DK X RF

Q083. Do you have any other health insurance?								
1. YES 0. NO (0	30 TO -> (Q085)	W. DK (GO TO -> Q085) X RF (GO TO -> Q085)						
Q084 Is it	?							
			1	0	W	X		
	An HMO with its own sta (like Kaiser, FHP, or Ma		YES	NO	DK	RF		
	A plan that lists physicia use (like Prudential, Hea	YES rica)	NO	DK	RF			
Q084c. (like l	YES	NO	DK	RF				
Q084d. C	Other (Specify)		YES	NO	DK	RF		
NOTE: FOR	R Q085: 082, OR Q083 = '1', ASF	(Q085, OTHERWISE GO TO Q08	6					
Q085. Does	s your health insurance o	cover the cost of a PSA blood test?						
1. YES 0. NO	W. X F							
		screening is for check-up purpos body like yourself who has a clo						
At what age	e should he have his firs	t PSA? Would you say at age?						
1. 30 2. 40 3. 50 4. 60		W. DK X RF						
Q087. How	often should a man suc	h as yourself have a PSA test? Wo	uld you	say?				
 Even Even Even 	y 6 months y year y 2-3 years y 3-5 years y 5-10 years	W. DK X RF						

NOTE FOR Q088 & Q089:

* IF RID = "2", CHOOSE SON; IF RID = "4" CHOOSE BROTHER; IF RID = "6" CHOOSE FATHER 33% OF SUBJECTS WILL RANDOMLY BE ASSIGNED TO RECEIVE SNR1; 33% OF SUBJECTS WILL BE RANDOMLY ASSIGNED TO RECEIVE SNR2; 33% OF SUBJECTS WILL BE RANDOMLY ASSIGNED TO RECEIVE SNR3. SNR3 WILL RECEIVE NO TEXT AND NO QUESTIONS Q088 AND Q089. SNR3 SUBJECTS WILL GO AUTOMATICALLY FROM Q087 TO Q092

Q088. (SNR1) SCENARIO ONE: A scenario for a random 33% of the sample will read as follows:

"Earlier, I described the PSA blood test. Now, as you may know, prostate cancer is the second leading cause of death from cancer in men. Having a BROTHER, FATHER, SON with prostate cancer increases your risk of getting prostate cancer. Doctors agree that early detection of prostate cancer is important. But doctors disagree about the widespread use of the PSA blood test as a screening test.

Some doctors feel that the PSA blood test is not very accurate. Suppose a man has a **high PSA blood level**. This may mean that he has cancer, but it may also mean that his prostate is just swollen (known as BPH) and that he may not have cancer. Because you don't know what it is, he may have to have a biopsy to know for sure. In a biopsy, a small tissue sample is taken from the prostate for further checking.

Now, suppose a man has a **normal PSA blood level**. Most of the time a normal PSA blood level may mean that a person does not have cancer. However, men can have a normal PSA blood level and have cancer.

Currently, the PSA blood test is the only test available. That's why many doctors, as well as the American Cancer Society, highly recommend that men over 40 have an annual PSA blood test, especially if they have a family member with prostate cancer. They feel that a PSA blood test can detect prostate cancer early. And, 9 out of 10 cancers that are detected early can be cured.

Q088 (SNR2) SCENARIO TWO: A scenario for a random 33% of the sample will read as follows:

"Earlier, I described the PSA blood test. Now, as you may know, prostate cancer is the second leading cause of death from cancer in men. Having a **BROTHER**, **FATHER**, **SON** with prostate cancer increases your risk of getting prostate cancer. Doctors agree that early detection of prostate cancer is important. But doctors disagree about the widespread use of the PSA blood test as a screening test.

Currently, the PSA blood test is the only test available. That's why many doctors, as well as the American Cancer Society, highly recommend that men over 40 have an annual PSA blood test, especially if they have a family member with prostate cancer. They feel that a PSA blood test can detect prostate cancer early. And, 9 out of 10 cancers that are detected early can be cured.

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Now, suppose a man has a **normal PSA blood level**. Most of the time a normal PSA blood level may mean that a person does not have cancer. However, men can have a normal PSA blood level and have cancer.

Q088 (SNR3) SCENARIO THREE: NO TEXT AND NO QUESTIONS ASKED.

Given what you have heard ...

How likely are you to ask your doctor (or nurse) about getting screened for prostate cancer?

	very likely Somewhat likely Not likely	X RF	`			
Q089.	How likely are you to get a F	PSA blood te	est within the nex	tt 12 months?		
2.	Very likely Somewhat likely Not likely	W. DK X RF	(
NOTE	*** : Q090 AND 091 WERE DEL ***	ETED DUE	TO REDUNDAN	ICY. SAME QU	ESTION	IS AS Q088 AND Q089
CLIN	ICAL TRIALS					
prever treatm	As you may know, a clinion a disease or treat a dis	se. Some t	trials are done	vith cancer pat	ients to	test different
Have	you ever participated in a clin	ical trial?				
	YES NO (GO TO -> Q094)		((GO TO> Q0 (GO TO> Q09	,		
Q093.	What kind of trial was it? P	lease specif	y:			
W.	DK	X RF				
	DK Have you ever heard about Ovarian Cancer Screening	the Prostate	e Cancer Preven	tion Trial or the l	Prostate,	, Lung, Colorectal,
Q094.	Have you ever heard about Ovarian Cancer Screening YES W.	the Prostate	e Cancer Preven	tion Trial or the l	Prostate,	, Lung, Colorectal,
Q094. 1. 0. Q095. prevertake a not kr	Have you ever heard about Ovarian Cancer Screening YES W.	the Prostate Trial? DK RF ention Trial idy is free onen will be rug or a sug	l (PCPT) is a stu of charge. For 7 given the drug gar pill. At the c	idy to test whe years, 18,000 a and half will be end of 7 years,	ther the men acr	drug <i>finasterid</i> e can coss the country will a sugar pill. Men will
Q094. 1. 0. Q095. prevetake a not kr	Have you ever heard about Ovarian Cancer Screening YES W. NO X The Prostate Cancer Prevent prostate cancer. The stupill each day. Half of the roow if they are taking the divining the div	the Prostate Trial? DK RF ention Trial Idy is free onen will be rug or a sug which a sn	l (PCPT) is a stu of charge. For 7 given the drug gar pill. At the c nall sample of t	idy to test where years, 18,000 and half will be end of 7 years, issue is taken.	ther the men acr	drug <i>finasterid</i> e can coss the country will a sugar pill. Men will
Q094. 1. 0. Q095. prevetake a not kr	Have you ever heard about Ovarian Cancer Screening YES W. NO X The Prostate Cancer Prevent prostate cancer. The study pill each day. Half of the reach in the day of their prostate gland, in	the Prostate Trial? DK RF ention Trial Idy is free onen will be rug or a sug which a sn	l (PCPT) is a stu of charge. For 7 given the drug gar pill. At the c nall sample of t	idy to test where years, 18,000 and half will be end of 7 years, issue is taken.	ther the men acr	drug <i>finasterid</i> e can coss the country will a sugar pill. Men will
Q094. 1. 0. Q095. prevertake a not kr biops	Have you ever heard about Ovarian Cancer Screening YES W. NO X The Prostate Cancer Prevent prostate cancer. The stupill each day. Half of the row if they are taking the day of their prostate gland, in were asked to participate in a 1. YES	the Prostate Trial? DK RF ention Trial Idy is free of nen will be rug or a sug which a sn trial like thi W. DK X. RF	l (PCPT) is a stu of charge. For 7 given the drug gar pill. At the c nall sample of t	idy to test wher years, 18,000 and half will be end of 7 years, issue is taken. ticipate?	ther the men acr e given a all 18,00	drug <i>finasterid</i> e can coss the country will a sugar pill. Men will
Q094. 1. 0. Q095. prevertake a not kr biops	Have you ever heard about Ovarian Cancer Screening YES W. NO X The Prostate Cancer Prevent prostate cancer. The stupill each day. Half of the relow if they are taking the day of their prostate gland, in were asked to participate in a 1. YES 0. NO	the Prostate Trial? DK RF ention Trial Idy is free of nen will be rug or a sug which a sn trial like thi W. DK X. RF	l (PCPT) is a stu of charge. For 7 given the drug gar pill. At the c nall sample of t	idy to test wher years, 18,000 and half will be end of 7 years, issue is taken. ticipate?	ther the men acr e given a all 18,00	drug <i>finasterid</i> e can coss the country will a sugar pill. Men will

•									
Q096b. the possible side effects	1	0	W	X					
Q096c. having to get a biopsy	1	0	w	X					
Q097. Another clinical trial is the PLCO. This is a health study to see if a PSA blood test and a rectal exam can detect prostate cancer early. The study is free of charge and will involve 74,000 men nationwide. Half the men will receive the PSA blood test and a rectal exam once a year for 4 years and half will not receive the tests at all. All the men, whether they receive the tests or not, will have to fill out a questionnaire each year.									
If you were asked to participate in a tria	al like this, would yo	u participate?							
1. YES 0. NO	W. DK X RF								
Q098. Which of the following would be	e a reason for you n	ot to participate	in the trial?						
	YES	NO	DK	RF					
Q098a. having to get blood test	1	0	W	X					
Q098b. having to get a rectal exam	1	0	W	X					
Q098c. having to fill out questionnaires	s 1	0	W	X					
Q099. There is a new clinical trial the nationwide taking specific vitamins. This trial would not require men to the liftyou were asked to participate in a trial.	and minerals for a take medications o	minimum of 7 r get a biopsy.	years and a			rs.			
1. YES 0. NO	W. DK X RF								
Q100. Which of the following would be	e a reason for you n	ot to participate	in the trial?						
	YES	NO	DK	RF					
Q100a. having to take vitamins	1	0	W	X					
Q100b. the length of the trial (7-12 yrs)	1	0	W	X					
Q101. There are many reasons peop the following reasons apply to you.	ole give for not par	ticipating in cl	inical trials.	Please	tell me if any	y of			
		Yes	No	DK	RF				
Q101a. Afraid of being used as a guir	nea pig	1	0	W	X				

0

Χ

Χ

Q101b. Afraid you'll get cancer as a result of participating 1

Q101d. Nev	ver thought about it	1	0	W	Χ	
Q101e. Doo	ctor never recommended it	1	0	W	X	
Q101f. It is	associated with homosexuality	1	0	W	X	
Q101g. It is	too uncomfortable or painful	1	0	W	X	
Q101h. Can you think of any other reasons why you would not participate?						

Q102. Please tell me whether you agree or disagree with the following statements.

	Agree	Disagree	No Opinion	DK	RF
Participating in these clinical trials will help others.	1	0	2	W	X
Q103. Participating in these clinical trials will prolong my life.	1	0	2	W	X
Q104. I may learn something that will benefit my health.	1	0	2	W	X

Q105. This concludes the survey. Before I hang up, I'd like to tell you something about prostate cancer. Earlier in the interview, I asked you about what you think makes a man more likely to get prostate cancer. We think it's important to tell everyone we talk to what is known scientifically about prostate cancer. The following things are believed by scientists to make a man more likely to get prostate cancer. A combination of them increases the risk even more.

- older age (over 55 years old)
- having relatives with prostate cancer (especially a father, brother, or son)
- having a relative diagnosed before the age of 60
- being African American

You should also know that exercise and eating a low-fat diet may decrease your risk.

Q106. Many men believe other things make a man more likely to get prostate cancer which are not true. The following things are not related to prostate cancer.

- too much stress
- too much sex
- lack of sex
- sitting on cold surfaces

Also, drinking alcohol has not been scientifically proven to cause prostate cancer.

Q107. If you would like more information about prostate cancer, early detection and treatment, you can call the Cancer Information Service. Would you like the number?

- 1 YES [1-800-422-6237]
- 0 NO

***** NOTE FOR Q108M: PLEASE DISPLAY RADDRES1, RADDRES2, RCITY, RSTATE, RZIP, RPHONE1, RPHONE2, AND RPHONE3 FROM RELATIVE TRACKING DATABASE 111 Q108M I would like to verify your address so that I can send you some information. I would also like to get another telephone number where we can reach you or leave you a message. (REPEAT ADDRESS AND PHONE NUMBER ON FILE-SPECIFY NEW ADDRESS AND PHONE NUMBERS (Q108M MEMO FIELD). (BLANK O.K.) ENTER Y IF ADDRESS ETC. CHANGED . = = UPPER CASE ONLY Q109. If we do a follow-up study in the future, may we contact you again? 1. YES W. DK 0. NO X. RF On behalf of our project, I'd like to thank you for the time you dedicated to this survey. Good - bye. !!! RID: THE INTERVIEW OF THIS RELATIVE IS OVER! STATUS CODE OF THIS CASE'S INTERVIEW RECORD: LANGUAGE OF INTERVIEW (E/S):

PREVIOUSLY RECORDED INTERVIEWER:

INTERVIEWER TO BE RECORDED:

2 OR 3 LETTER INITIALS, NO SPACE OR SYMBOL,
WILL BE CONVERTED TO UPPER CASE AUTOMATICALLY

NOTE FOR 1st PARAGRAPH: * IF RID = '2' CHOOSE HIJO; IF RID = '4' CHOOSE HERMANO; IF RID = '6' AND PSEX = '2' CHOOSE PAPA.								
* INSERT PTFNAME AND PTLNAME IN SECOND BLANK *******								
Hola, mi nombre es, le estoy llamando del Programa Familias Saludables en UCLA. Estamos haciendo una encuesta de la salud. Recibimos su nombre de su [HERMANO, PAPA, HIJO] [FIJAR NOMBRE]. ¿Le habló el sobre este estudio?								
	□ SI □ NO		Me da gusto. Dejeme recordarle que Dejeme explicarle que					
Este estudio esta dirigido por el Centro de Cáncer en UCLA. Estamos entrevistando a familiares cercanos de pacientes con cáncer de la próstata. La entrevista tomara aproximadamente 20 minutos y le preguntaremos sus opiniones , creencias sobre el cáncer, sus costumbres, y algunos antecedentes sobre su salud. Sus repuestas ayudaran a desarrollar programas para educar a las personas sobre la detección temprana del cáncer de la próstata.								
¿Recientemente le enviamos algunos materiales explicandole el estudio, los recibió? Dejeme asegurarle que todas sus respuestas serán confidenciales. Toda información se utilizara solamente para este estudio. Ninguna información que lo identifique sera revelada sin su consentimiento. Usted puede parar la entrevista a cual quier momento.								
Si usted desea y tiene alguna pregunta, le puedo dar el numero de la Doctora Bastani, quien conduce este estudio. (DR. BASTANI'S NUMBER IS: 310-206-9266; RESPONDENTS MAY CALL COLLECT).								
También le puedo dar el numero de la Oficina de Protección a Sujetos de Investigación en UCLA, 2107 Peter V. Ueberroth Building, Box 951694, Los Angeles, CA 90095-1694, (310) 825-8714.								
Q0A	¿Estarí	a dispue	sto a contestar algunas preguntas?					
	(1)	SI ->	Continue					
	(0)	NO	Entiendo su decisión. Si tiene alguna pregunta sobre el cáncer de la próstata, la detección temprana, y sus tratamientos, puede llamar al Servicio de Información Sobre el Cáncer. ¿Le gustaría el numero? (1-800-422-6237 o 1-800-4-CÁNCER). Si cambia de opinión y quiere participar, por favor llamenos gratis al numero 1-877-278-8505. Gracias y adiós.					
O0B	; Tiene	tiempo :	ahora?					

Dejeme asegurarle que ninguna respuesta es correcta o incorrecta. Estamos interesados en saber que es lo que usted siente y cree sobre el cáncer de la próstata.

Continue

¿Cuando le puedo llamar?____

(1) SI -> (0) NO->

* ASK IF PLET1STA ='1' AND RAGE <>'--' OTHERWISE GO TO 003 * IF RID = '2' CHOOSE HIJO; IF RID = '4' CHOOSE HERMANO; IF RID = '6' CHOOSE PAPA * INSERT PTFNAME AND PTLNAME IN FIRST BLANK * INSERT RAGE IN SECOND BLANK ***** O001 Empezáremos por verificar su edad. Su [HERMANO, PAPÁ, HIJO] [FIJAR NOMBRE] nos dijo que usted tiene_____ años. ¿Esto es correcto? 1 SI (GO TO ->Q04) 0 NO W DK X RF ***** NOTE FOR Q002: * IF Q002 \geq 40 OR Q002 \leq 75, GO TO -> Q004 * IF Q002 < 40 OR Q002 > 75, GO TO -> Q003w * IF RID = '2' CHOOSE HIJO; IF RID = '4' CHOOSE HERMANO; IF RID = '6' CHOOSE PAPÁ (Q002) ¿Le molestaría si verificamos su edad? (RAGE) WW DK XX RF IF CASE DID NOT RETURN MATERIALS, OR DID NOT GIVE US THE AGE(S), PLEASE SAY ... ****** NOTE FOR Q003: * IF Q003 < 40 OR Q003 > 75, GO TO -> Q003w * IF Q003 \geq 40 OR Q003 \leq 75, GO TO -> Q004 (Q003) Su [HERMANO, HIJO, PAPÁ] no me dijo su edad. ¿Le molestaría decirme cuantos anos tiene?____(RAGE) WW DK XX RF IF PARTICIPANT IS UNDER 40 YEARS OF AGE OR OVER 75 YEARS OF AGE, THEY ARE NOT ABLE TO PATICIPATE. PLEASE SAY,... (Q003w)Gracias. Agradezco su deseo de participar en este momento. Desafortunadamente, la encuesta telefónica es solamente para personas entre la edad de 40 a 75 años. ¿Tiene alguna pregunta para

mi antes de terminar la llamada? Gracias por su tiempo. Adiós.

NOTE FOR Q001:

	¿Alguna vez su doctor le dijo q	ue tiene o que ha tenido algún tipo de cáncer?
	1 SI 0 NO	(GO TO -> Q007)
	W DK X RF	(GO TO -> Q007) (GO TO -> Q007)
Q005	¿Que tipo de cáncer?	
	(Q05a)(Q05b)(Q05	5c)
	1 COLON 2 PRÓSTATA 3 PULMONES	(GO TO -> Q007)
	V Other -> specify W DK X RF	_(Q005v) (GO TO -> Q007) (GO TO -> Q007) (GO TO -> Q007)
Q006	Desafortunadamente, la encues	e agradezco su deseo de participar en este estudio. ta telefónica se esta haciendo solamente con personas que no ta. ¿Tiene algunas preguntas para mi antes de terminar la o. Adiós.
Q007	En general, diría usted que su s	alud es
	1 excelente 2 muy buena 3 buena 4 regular 5 mala	
	W DK X RF	
Q008		tor que tiene la próstata agrandada o hinchada? Esto erplasia prostático benigno (BPH).
	1 SI 0 NO	
	W DK X RF	
Q009	¿Alguna vez le ha dicho un doc	etor que tiene algún otro problema serio de salud?
	1 SI -> specify 0 NO	(Q009s)
	W DK X RF	
****	***	

Q004 Ahora me gustaría hacerle algunas preguntas sobre su salud.

NOTE FOR Q010:				
* IF RID = '2' CHOOSE HIJO; IF RID = '4' CHOOSE HERMANO; IF RID = '6' CHOOSE PAPÁ * INSERT PTFNAME IN FIRST BLANK * IF RID = "6", AFTER ASKING Q010, SKIP TO Q012. ********				
Comenzaremos con su [PA	APÁ, HERMANO, HIJO]_	bre su familia y la salud de ellos. quien lo recomendó para este a próstata, ha sido el diagnosticado con		
1 SI				
0 NO	(GO TO -> Q011)			
W DK X RF	(GO TO -> Q011) (GO TO -> Q011)			
¿Que tipo de cáncer?	¿A que edad fue diagno	osticado?		
(Q010a1) (Q010a2)	(Q010b1) (Q010b2)			
TIPO DE CÁNCER:				
1 COLON 2 PRÓSTATA 3 SENO 5 PULMONES				
V OTRO W DK X RF				
Q011 ¿A su PAPÁ lo han diagno	sticado con cáncer?	_		
1 SI 0 NO	(GO TO -> Q012)			
W DK X RF	(GO TO -> Q012) (GO TO -> Q012)			
	lad fue diagnosticado?	¿Su PAPÁ es(1)su papá biológico o (2) su padrastro?		
(Q011a1) (Q011b1) (Q011a2) (Q011b2)		(Q011c)		
TIPO DE CÁNCER:				
1 COLON 2 PRÓSTATA 3 SENO 4 PULMONES				
V OTRO W DK X RF Q012 ;Ha sido su MAMÁ diagnosticada con cáncer?				

1 SI 0 NO	(GO TO ->Q013)	
W DK X RF	•	GO TO ->Q013) GO TO ->Q013)	
Que tipo de cáncer?	A que edad fue o	diagnosticada?	Su MAMÁ es(1) su mamá biológica o (2) su madrastra
(Q012a1) (Q012a2)	(Q012b1) (Q012b2)	_ (W=DK X=R _ (W=DK X=R	
TIPO DE CÁNCER:			
1 COLON 3 SENO 4 CERVIZ 5 PULMONES 6 OVARIOS 7 ENDOMETRIO			
V OTRO W DK X RF			
******* NOTE FOR Q013: ONLY DISPLAY THE OQ013a ******** Q013 ¿Han sido algun			BROTHER SECTIONS INDICATED IN
1 SI -> Cuantos	s?(Q	013a)	
0 NO W DK		O TO -> Q014)	
X RF		O TO -> Q014) O TO -> Q014)	
HERMANO 1: ¿Que tipo de cáncer?	٨j	que edad fue diag	gnosticado?
(Q013a1) (Q013a2)	(Q((Q(013b1) 013b2)	
TIPO DE CÁNCER:			
1 COLON 2 PRÓSTATA 3 SENO 4 PULMONES			
V OTHER W DK X RF			

1 su hermano biológico (GO TO -> Q013a3) 2 su medio hermano 3 su hermanastro (GO TO -> Q013a3) W DK $(GO\ TO \rightarrow Q013a3)$ X RF $(GO\ TO \rightarrow Q013a3)$ Q013d ¿Es su medio hermano por parte de su MAMÁ o de su PAPÁ? 1 MAMÁ 2 PAPÁ W DK X RF **HERMANO 2:** ¿Que tipo de cáncer? ¿A que edad fue diagnosticado? (Q013a3)____ (Q013b3) (Q013a4) (Q013b4) TIPO DE CÁNCER: 1 COLON 2 PRÓSTATA 3 SENO 5 PULMONES V OTRO W DK X RF Q013e Su hermano es ... 1 su hermano biológico $(GO\ TO \rightarrow Q013a5)$ 2 su medio hermano 3 su hermanastro $(GO\ TO -> Q013a5)$ W DK $(GO\ TO \rightarrow Q013a5)$ X RF (GO TO -> Q013a5) Q013f Es su medio hermano por parte de su MAMÁ o de su PAPÁ? 1 MAMÁ 2 PAPÁ W DK X RF

O013c Su hermano es...

HERM	ANO 3:			
¿Que tipo de cáncer? ¿A que edad fue diagnosticado?				
(Q12a5 (Q12a6)	(Q12b5) (Q12b6)	(W=DK (W=DK	
TIPO D	DE CÁNCER:			
3 SEN	STATA			
V OTI W DK X RF				
Q013g	Su hermano es			
	1 su hermano biológico 2 su medio hermano	(GO TO -	-> Q014)	
	3 su hermanastro	(GO TO -	-> Q014)	
	W DK X RF	(GO TO - (GO TO -		
Q013h ¿Es su medio hermano por parte de su MAMÁ o de su PAPÁ?				
	1 MAMÁ 2 PAPÁ			
	W DK X RF			
	FOR Q014: DISPLAY THE CORRESPO	NDING NUMBER OF SIS	STER SECTIO	ONS INDICATED IN
Q014	¿Han sido algunas de sus her	rmanas diagnosticadas con	cáncer?	
	1 SI -> Cuantas? 0 NO	(Q014a) (GO TO -> Q015)		
	W DK X RF	(GO TO -> Q015) (GO TO -> Q015)		
HERM	ANA 1:			
¿Que tipo de cáncer? ¿A que edad fue diagnostica			ticada?	
(Q014a (Q014a	n1) n2)	(Q014b1) (Q014b2)		

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TIPO DE CÁNCER:	
1 COLON 3 SENO 4 CERVIZ 5 PULMONES 6 OVARIOS 7 ENDOMETRIO	
V OTRO W DK X RF	
Q014c Su hermana es	
1 su hermana biológica	(GO TO ->Q014a3)
2 su media hermana 3 su hermanastra	(GO TO ->Q014a3)
W DK	(GO TO ->Q014a3)
X RF	(GO TO ->Q014a3)
Q014d ¿Es su media hermana por p	oarte de su MAMÁ o de su PAPÁ?
1 MAMÁ 2 PAPÁ	
W DK X RF	
HERMANA 2:	
¿Que tipo de cáncer?	¿A que edad fue diagnosticada?
(Q014a3)	(Q014b3)
(Q014a4)	(Q014b4)
TIPO DE CÁNCER:	
1 COLON 3 SENO 4 CERVIZ 5 PULMONES 6 OVARIOS 7 ENDOMETRIO	
V OTRO W DK X RF	

O014e Su hermana es 1 su hermana biológica (GO TO -> Q014a5) 2 su media hermana 3 su hermanastra $(GO\ TO \rightarrow Q014a5)$ W DK $(GO\ TO \rightarrow Q014a5)$ X RF (GO TO -> Q014a5) Q014f ¿Es su media hermana por parte de su MAMÁ o PAPA? 1 MAMÁ 2 PAPA W DK X RF HERMANA 3: ¿Que tipo de cáncer? ¿A que edad fue diagnosticada? (Q014b5)_____ (Q014a5)____ (Q014a6) (Q014b6) TIPO DE CÁNCER: 1 COLON 3 SENO 4 CERVIZ 5 PULMONES 6 OVARIOS 7 ENDOMETRIO V OTRO W DK X RF Q014g Su hermana es.. 1 su hermana biológica (GO TO -> Q015) 2 su media hermana 3 su hermanastra (GO TO -> Q015) W DK (GO TO -> Q015) X RF (GO TO -> Q015) Q014h ¿Es su media hermana por parte de su MAMÁ o de su PAPÁ? 1 MAMÁ 2 PAPÁ W DK

	FOR Q015: DISPLAY THE CORRES	PONDING NUMBER OF SON SECTIONS INDICATE	DIN Q015a
Q015	¿Han sido algunos de sus hijos diagnosticados con cáncer?		
	1 SI -> Cuantos? 0 NO	(Q015a) (GO TO ->Q016)	
	W DK X RF	(GO TO ->Q016) (GO TO -> Q016)	
HIJO 1	1:		
¿Que t	ipo de cáncer?	¿A que edad fue diagnosticado?	
(Q015a)	a1) a2)	(Q015b1) (Q015b2)	
TIPO I	DE CÁNCER:		
3 SEN	STATA		
V OTF W DK X RF			
Q015c	Es su hijo		
	1 su hijo biológico2 su hijo adoptivo3 su hijastro		
	W DK X RF		
HIJO 2 ¿Que t	2: ipo de cáncer?	¿A que edad fue diagnosticado?	
(Q015a	a3) a4)	(Q015b3) (Q015b4)	
TIPO I	DE CÁNCER:		
3 SEN	STATA		
V OTF W DK			

Q015d Es su hijo	
1 su hijo biológico2 su hijo adoptivo3 su hijastro	
W DK X RF	
HIJO 3:	
¿Que tipo de cáncer?	¿A que edad fue diagnosticado?
(Q015a5) (Q015a6)	(Q015b5) (Q015b6)
TIPO DE CÁNCER:	
1 COLON 2 PRÓSTATA 3 SENO 5 PULMONES	
V OTRO W DK X RF	
Q015e Es su hijo	
1 su hijo biológico2 su hijo adoptivo3 su hijastro	
W DK X RF	
******* NOTE FOR Q016: ONLY DISPLAY THE CORRESPONIN Q016a *******	NDING NUMBER OF DAUGHTER SECTIONS INDICATED
Q016 ¿Han sido algunas de sus hijas	diagnosticadas con cáncer?
1 SI -> Cuantas? (Q016a) 0 NO	(GO TO -> Q017)
W DK X RF	(GO TO -> Q017) (GO TO -> Q017)

HIJA 1: ¿Que tip	oo de cáncer?	¿A que edad fue diagnosticada?
(Q016a (Q016a)	1) 2)	(Q016b1) (Q016b2)
TIPO D	E CÁNCER:	
6 OVA	O VIZ MONES	
V OTF W DK X RF	RO	
Q016c	Es su hija	
	1 su hija biológica2 su hija adoptiva3 su hijastra	
	W DK X RF	
HIJA 2	•	
	po de cáncer?	¿A que edad fue diagnosticada?
(Q016a (Q016a	3) 4)	(Q016b3) (Q016b4)
TIPO D	E CÁNCER:	
6 OVA	O VIZ MONES	
V OTR W DK X RF		
Q016d	Es su hija	
	1 su hija biológica 2 su hija adoptiva 3 su hijastra	
	W DK	

HIJA 3	:					
¿Que ti	po de cáncer?	¿A que edad fu	e diagnostica	ada?		
(Q016a (Q016a	5) 6)	(Q016b5) (Q016b6)		(W=DK (W=DK		
TIPO D	DE CÁNCER:					
6 OVA	O VIZ MONES					
V OTI W DK X RF	RO					
Q016e	Es su hija					
	 su hija biológica su hija adoptiva su hijastra 					
	W DK X RF					
*****	**					
ONLY	FOR Q017: DISPLAY THE CORRESTATED IN Q017a **	PONDING NU	MBER OF	GRANDF	ATHER	SECTIONS
Q017	¿Han sido algunos de sus abu	elos diagnostica	dos con cánc	er?	_	
	1 SI> Cuantos?(0 NO	Q017a)	(GO	ГО -> Q018	3)	
	W DK X RF			ГО -> Q018 ГО -> Q018		

ABUELO 1:	
¿Que tipo de cáncer?	¿A que edad fue diagnosticado?
(Q017a1) (Q017a2)	(Q017b1) (Q017b2)
TIPO DE CÁNCER:	
1 COLON 2 PRÓSTATA 3 SENO 5 PULMONES	
V OTRO W DK X RF	
Q017c ¿Es su abuelo materno o pate	erno?
1 MATERNO 2 PATERNO	
W DK X RF	
ABUELO 2:	
¿Que tipo de cáncer?	¿A que edad fue diagnosticado?
(Q017a3) (Q017a4)	(Q017b3) (Q017b4)
TIPO DE CÁNCER:	
1 COLON 2 PRÓSTATA 3 SENO 5 PULMONES	
V OTRO W DK X RF	
Q017d ¿Es su abuelo materno o pate	erno?
1 MATERNO 2 PATERNO	
W DK X RF	

*****	**	
NOTE FOR Q018: ONLY DISPLAY THE CORRESPONDING NUMBER OF SISTER SECTIONS INDICATED IN Q018a ********		
Q018	¿Han sido algunas de sus abu	elas diagnosticadas con cáncer?
	1 SI -> Cuantas?(QO 0 NO	(GO TO -> Q019)
	W DK X RF	(GO TO -> Q019) (GO TO -> Q019)
ABUE	LA 1:	
¿Que ti	po de cáncer?	¿A que edad fue diagnosticada?
(Q018a (Q018a	2)	(Q018b1) (Q018b2)
TIPO I	DE CÁNCER:	
6 OVA	O VIZ MONES	
V OTF W DK X RF		
Q018c ¿Es su abuela materna o paterna?		
	1 MATERNA 2 PATERNA	
	W DK	

ABUELA 2:	
¿Que tipo de cáncer?	¿A que edad fue diagnosticada?
(Q018a3) (Q018a4)	(Q018b3) (Q018b4)
TIPO DE CÁNCER:	
1 COLON 3 SENO 4 CERVIZ 5 PULMONES 6 OVARIOS 7 ENDOMETRIO V OTRO W DK X RF	
Q018d ¿Es su abuela materna o par	terna?
1 MATERNA 2 PATERNA W DK X RF	
Q019 ¿Hay alguien más en su fam	ilia que haya tenido cáncer?
1 SI 0 NO	(GO TO -> Q021)
W DK X RF	(GO TO -> Q021) (GO TO -> Q021)

Q 020	¿Quien?		
¿Relaci	ión?	¿Tipo de cáncer?	¿A que edad fue diagnosticado/a?
(Q021a	n1) n2) n3)	(Q021b1) (Q021b2) (Q021b3)	(Q021c1) (Q021c2) (Q021c3)
RELAC	CIÓN		
1 SOB 2 SOB 3 TÍA 4 TÍO 5 PRIM 6 NIE 7 NIE	RINO MO/A TA		
V OT W DK X RF			
TIPO I	DE CÁNCER:		
3 SEN 4 CER 5 PUL 6 OV	STATA O VIZ MONES		
V OTR W DK X RF	RO		
* IF RII	FOR Q021: D = '2' CHOOSE RT PTFNAME IN		OSE HERMANO; IF RID = '6 CHOOSE PAPÁ
Q021	Ahora piense e	n su [PAPÁ, HERMAN	IO, HIJO] que tuvo cáncer de la próstata
	¿Como califica es	aría su salud ahora con r	respecto al cáncer de la próstata? Diría que
	1 Excelente 2 Muy buena 3 Buena 4 Regular 5 Mala W DK X RF	ι	

* IF RID = '2' CHOOSE HIJO; IF RID = '4' CHOOSE HERMANO; IF RID = '6 CHOOSE PAPÁ Q022 Diría usted que el cáncer de la próstata de su [PAPÁ, HERMANO, HIJO] ha... 1 regresado 2 no ha regresado 3 desarrollado a otras partes del cuerpo W DK X RF ***** NOTE FOR Q023: * IF RID = '2' CHOOSE HIJO; IF RID = '4' CHOOSE HERMANO; IF RID = '6 CHOOSE PAPÁ Q023 Cree usted que el tratamiento y la recuperación del cáncer de la próstata de su [PAPÁ, HERMANO, HIJO] fue... 1 muy difícil 2 un poco difícil 3 nada difícil W DK X RF Q024 Ahora me gustaría hacerle unas preguntas acerca de sus sentimientos sobre el cáncer de la próstata. ¿Con que frecuencia piensa usted en la posibilidad de desarrollar cáncer de la próstata? Diría que.... 1 muy seguido 2 de vez en cuando 3 nunca W DK X RF O025 ¿Que tan preocupado esta de que pueda desarrollar cáncer de la próstata? Diría que... 1 muy preocupado 2 algo preocupado 3 nada preocupado W DK X RF Q026 ¿Cuando piensa en la posibilidad de desarrollar cáncer de la próstata, que tan temeroso se pone? Diría que... 1 muy temeroso W DK X RF 2 algo temeroso 3 nada temeroso

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NOTE FOR O022:

Q027	¿Diría que usted esta muy nervioso, algo nervioso, o nada nervioso de que pueda desarrollar cáncer de la próstata?
	1 muy nervioso 2 algo nervioso 3 nada nervioso
	W DK X RF
Q028	¿Piensa, mas de lo que usted desea, en que pueda desarrollar cáncer de la próstata?
	1 SI 0 NO
	W DK X RF
Q029	Ahora, me gustaría hacerle algunas preguntas acerca de su salud y algunos exámenes preliminares del cáncer de la próstata
	¿Con que frecuencia hace ejercicio? Diría que
	1 Diario o mas de tres veces a la semana2 Una a tres veces a la semana3 No hace ejercicio regularmente
	W DK X RF
Q030	¿Durante los últimos 12 meses, ha tenido un examen físico completo?
	1 SI 0 NO
	W DK X RF
Q031	Un examen que se hace para detectar el cáncer de la próstata es el DRE o sea examen digital del recto. Para este examen un dedo es introducido en el recto para examinar el área por algún problema con la próstata y el intestino mayor. ¿Algun vez usted ha oído hablar de este análisis?
	1 SI 0 NO
	W DK X RF

Q032	¿Ha tenido alguna vez un examen digital del recto- DRE?	
	1 SI 0 NO	(GO TO - Q034)
	W DK X RF	(GO TO - Q034) (GO TO - Q034)
Q033	¿Cuando fue su examer	mas reciente digital del recto?
	1 en los últimos 12 me 2 de 1 a 2 anos 3 de 3 a 5 años 4 mas de 5 años	eses
	W DK X RF	
Q034	detectar cáncer de la pre	igital del recto, existe un análisis de sangre que se usa para óstata. Este análisis de sangre se llama PSA o sea de la próstata". ¿Ha tenido usted alguna vez un análisis de
	1 SI 0 NO	
	W DK X RF	
Q035	¿Le ha recomendado su	doctor (o enfermera) que se haga un análisis de sangre PSA?
	1 SI 0 NO	
	W DK X RF	
Q036	¿Le ha recomendado su	doctor (o enfermera) que <u>no</u> se haga un análisis de sangre PSA?
	1 SI 0 NO	
	W DK X RF	
Q037	¿Ha tenido usted alguna	a vez un análisis de sangre PSA?
	1 SI 0 NO (GO TO Q041)	
	W DK (GO TO Q041) X RF (GO TO Q041)	

Q038	¿Cuantos análisis PSA ha tenido? ¿Diría que?
	1 uno 2 mas de uno
	W DK X RF
Q039	¿Cuando fue su análisis de sangre PSA mas reciente? Diría que fue
	1 en los últimos 12 meses 2 de 1 o 2 anos 3 de 3 a 5 años 4 mas de 5 años
	W DK X RF
Q040	¿Por que le hicieron el análisis PSA? Fue por algún problema de salud o como parte de un examen de rutina?
	1 POR UN PROBLEMA DE SALUD 2 PARTE DE UN EXAMEN RUTINARIO
	V OTHER (Specify)(Q040s) W DK X RF
Q041	¿Alguna vez a ido con un urólogo? Un urólogo es un doctor que se especializa en los problemas de los riñones, vesícula, testículo y próstata.
	1 SI 0 NO
	W DK X RF
Q042	Una sigmoidoscopia o colonoscopia es cuando un instrumento largo y flexible con una luz terminal se introduce al recto y al colon para examinar posibles problemas. ¿Había usted oído hablar de este examen?
	1 SI 0 NO
	W DK X RF
Q043	¿Ha tenido usted alguna vez una sigmoidoscopia o una colonoscopia?
	1 SI 0 NO (GO TO Q045)
	W DK (GO TO Q045) X RF (GO TO Q045)

1 en los últimos 12 meses 2 de 1 o 2 anos 3 de 3 a 5 años 4 mas de 5 años W DK X RF Q045 Un análisis que se hace para detectar el cáncer del colon es el examen de excremento que detecta si hay sangre en el excremento. Para este examen usted pone una poco de su excremento en una tarjeta, todos los días por 3 días. Usualmente se le pedirá que se abstenga de comer carne roja o ciertas frutas y vegetales durante el examen. ¿Alguna vez ha oído hablar del examen de excremento que detecta sangre? 1 SI 0 NO W DK X RF ¿Alguna vez se ha hecho en casa el examen de excremento que detecta sangre? 0 NO (GO TO Q048) W DK (GO TO Q048) X RF (GO TO Q048) Q047 ¿Cuando se hizo el examen mas reciente de excremento para detectar sangre? Diría que fue... 1 en los últimos 12 meses 2 de 1 o 2 anos 3 de 3 a 5 años 4 mas de 5 años W DK X RF Ahora le voy hacer algunas preguntas solamente para propósitos de estadísticas generales. Recuerde que sus preguntas son confidenciales. ¿Cual es el nivel de educación mas alto que usted ha completado? NINGUNA ESCUELA 00 ESCUELA ELEMENTARÍA 01 02 03 04 05 06 07 08 09 SECUNDARIA 10 11 12 **UNIVERSIDAD** 13 14 15 16 17 18 19 20 W DK X RF

¿Cuando fue su mas reciente sigmoidoscopia o colonocopia? Diría usted que fue...

O044

Q049	¿Nació usted en los Estados Unidos?		
	1 SI	(CO TO > 0052)	
	0 NO	(GO TO -> Q052)	
	W DK		
	X RF		
Q050	¿En que país nació?		
	W DK		
	X RF		
Q051	¿Cuanto tiempo tiene viviendo en los (Q051yy)Años: (Q0		_
	W DK X RF		
Q052	¿Se considera Usted?		
	1 Afro-Americano		
	2 Hispano / Latino		
	3 Asiático / Asiático-Americano 4 Blanco		
	5 Americano Indígena / Americano Na	ativo	
	6 Isleño del Pacifico		
	7 de dos razas o de diversas razas spec	eify	_(Q052s1)
	V Other: (specify)		_(Q052s2)
	W DK X RF		
*****	****		
NOTE	FOR Q053:		
	F Q052="7"		
*****	****		
Q053	¿Con cual nacionalidad se identifica m	nas?	
*****	****		
	FOR Q054:		
ASK IF	F Q052 = "1"		
	Es usted		
	1 Afro-Americano 2 Indio del Oeste (incluye Islas del Ca 3 Cubano 4 Sur Americano 5 Puertorriqueño	ribe)	
	V OTHER	(Q054s)	
	W DK	(<0.543)	
	X RF		

*****	***
	FOR Q055: F Q052="2" ****
Q055	Es Usted
	1 Mexicano 2 Mexicano Americano 3 Chicano 4 Centro Americano 5 Sur Americano 6 Puertorriqueño 7 Cubano
	V Other (Specify)(Q055s) W DF X RF
*****	***
	FOR Q056: F Q052="3" ****
Q056	Es Usted
	1 Chino 2 Japones 3 Filipino 4 Vietnamita 5 Camboyano 6 Indígena Asiático 7 Indonesio 8 Coreano
	V OTHER(Q056s) W DK
	X RF
Q057	Cual de las siguientes cantidades mejor describe el ingreso total en su hogar, o sea el ingreso total de todas las personas viviendo con usted. No necesito una cantidad exacta, solamente un estimado. Recuerde, sus respuestas son confidenciales. Diría que aproximadamente
	1 Menos de \$10,000 (0-833.33/mes) 2 \$10,000 - 24,000(833.33 - 2000/mes) 3 \$25,000 - 39,000 (2083.33 - 3250/mes) 4 \$40,000 - 54,000(3333.33 - 4583.33/mes) 5 mas de \$55,000 (mas de 4,583.33/mes)
	WDK

Q058	¿Es usted casado o esta viviendo como casado?	
	1 SI 0 NO	
	W DK X RF	
Q059	Ahora le voy a leer una lista de cosas que algunas personas piensan que hacen a un hombre mas probable de desarrollar cáncer de la próstata. Para cada una de estas preguntas digame si usted cree o no cree que hace a un hombre mas probable de desarrollar cáncer de la próstata.	
	"¿Cree usted quehace a un hombre mas probable de desarrollar cáncer de la próstata"?	
Q059a Q059b Q059c Q059d Q059f. Q059g Q059h Q059i Q059j		
	1 SI 0 NO 2 POSIBLEMENTE	
	W DK X RF	
Q060	¿Quien cree usted que desarrolla cáncer de la próstata con mas frecuencia? Diría que	
	 1 Blancos 2 Hispanos/Latinos 3 Afro-Americanos 4 Asiáticos/Asia-Americanos 	
	W DK X RF	
Q061	¿Que tan probable es que usted desarrolle cáncer de la próstata durante su vida? Diría usted	
	1 muy probable 2 poco probable 3 nada probable	
	W DK X RF	

Las siguientes preguntas son relacionadas con sus creencias acerca del análisis de sangre

Q062	¿Antes de que habláramos hoy, sabia usted que debe de tener un examen digital del recto cada año?
Q063	¿Sabia usted que debe de hacerse un análisis de sangre PSA cada año?
Q064	¿Esta temeroso de que le hagan estos análisis?
-	• —
Q065	¿Es importante para usted tener un análisis de sangre PSA?
Q066	¿Le seria a usted difícil pagar los costos de un análisis de sangre PSA?
Q067	¿Tiene temor que durante estos análisis demuestren que
	usted tiene cáncer de la próstata?
Q068	¿Se puede curar el cáncer de la próstata si es encontrado temprano?
Q069	¿Sabia usted que necesitaba este análisis?
Q070	¿Usted piensa que los análisis de la próstata pueden causar problemas sexuales?
Q071	¿Usted piensa que tendrá problemas en obtener transportación para ir a su cita con el
	doctor?
Q072	¿Cree usted que solamente necesita examinarse la sangre con un análisis de PSA nomas cuando un doctor lo recomienda?
	1 SI 0 NO
	W DK X RF
Q073	Diría usted que esta de acuerdo o no esta de acuerdo con las siguientes declaraciones:
	Los beneficios de un examen de sangre PSA son mayores que cualquier inconveniencia.
	1 esta de acuerdo 2 no esta de acuerdo
	W DK X RF
Q074	Uno solamente necesita un análisis preventivo de la próstata cuando tiene los síntomas.
	1 esta de acuerdo 2 no esta de acuerdo
	W DK X RF
Q075	Es mucha molestia tener que examinarse para el cáncer de la próstata y poco el beneficio que se obtiene.
	1 esta de acuerdo 2 no esta de acuerdo
	W DK X RF

PSA- Antígenos específicos de la próstata.

PROSTATE CANCER FOCUS GROUP QUESTIONS

Welcome and thank you all very much for your willingness to talk to us.

We, at UCLA, are developing some informational materials on prostate cancer for men ages 40-75. We are trying to get some ideas about how to best provide this important information so that people will take interest. We would like to get some ideas from you.

What I'd like to do is ask a few questions and get your responses. This should take no more than one hour. Because we would like to make sure we get everything everyone says, we'd like to tape record the meeting. All information will be confidential. We will not share it with anyone else. This is only for the purposes of not losing something that someone says. I may also take some notes as we go along. In order that we all feel comfortable talking, I would ask that everyone agree that anything shared in this room remain in the room. Your participation is completely voluntary and you do not have to respond to anything you don't want to. You may leave at any time. We would, however, like you to stay and give us your ideas. At the end of our discussion, I will give you \$25.00 for your participation.

- 1. Let's start with what you know about prostate cancer (or what do you think of when you think of prostate cancer)?
 - a. What do you think causes prostate cancer?
 - b. What are some of the types of tests done and how often should they be done?
 - c. Impressions about what it means to have prostate cancer.
- 2. Many men give a variety of reasons for not getting tested. What are some of the reasons you think men would <u>not</u> get tested?
 - a. Concrete barriers (i.e., money, transportation, time)
 - b. Emotional barriers (i.e., afraid, concern)
 - c. Lack of knowledge about getting tested
 - d. Lack of doctor recommendation
- 3. Has anyone ever suggested that you get your prostate checked?
 - a. Who?
 - b. Did you get tested?
 - c. Are you planning to?
 - d. Do you have family/friends that have had their prostate checked? Who?

- 4. A person who has a parent, brother, or children with prostate cancer is at greater risk of getting it themselves (first degree relatives). Knowing this, if you had a family member who had prostate cancer, would you get the recommended tests?
 - a. Why? Why not?
 - b. Would it help to know your level of risk (i.e., 2-3x greater risk)
 - c. Would you talk to your doctor about getting tested if s/he did not recommended it?
- 5. If you were called on the telephone and told that your name was received from one your family members, and asked to complete a brief survey on prostate cancer over the telephone, would you be willing to do so?
 - a. Why? Why not?
 - b. What could the caller do to increase the chances that you might respond to the survey?
 - c. Would it make it easier for you to talk to a male/female or no difference?
- 6. Have you ever heard of the term 'clinical trial'?
 - a. How would you explain it to your friends/family?
 - b. Would you participate in one? Why? Why not?
 - c. What incentives would you need to participate in a prostate clinical trial?
- 7. Psychological Distress
 - a. Hand out questionnaire.
 - b. Can you think of other questions that capture distress?
- 8. Titles for the project:
 - c. "Living Longer' project